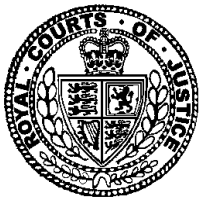

Neutral Citation Number: [2024] EWHC 61 (Fam)

Case No: FD2300605

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 17 January 2024

Before:

Mr Justice Poole

- -

Between:

Re NR (A Child: Withholding CPR)

KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST **Applicant**

- and –

(1) MRS R
(2) MR R
(3) NR (By his Children's Guardian)

Click here to enter text. **Respondents**

- -
- -

Nageena Khalique KC (instructed by Hill Dickinson LLP) for **the Applicant**
Katie Gollop KC and Myles Jackson (instructed by Scott Moncrieff & Associates Ltd) for **the First and Second Respondents**
Rhys Hadden (instructed by Cafcass Legal Services on behalf of the Children's Guardian) for **the Third Respondent**

Hearing dates: 15-17 January 2024

- -

JUDGMENT

This judgment is approved for publication. In any published version of the judgment the anonymity of NR, and Mr and Mrs R, the Guardian, and the treating clinicians must be strictly preserved in accordance with the Order of the Court. 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 Poole:

1. NR was born in March 2020, the first and only child of the First and Second Respondents. They are devoted parents who had long wanted, but for many years were unable, to have children. Mrs R's pregnancy with NR and his birth were sources of great joy to them and they are devoted to him. Sadly, NR was born with severe disabilities and life-limiting health conditions including a significant brain malformation. He suffers seizures which are not fully controlled by medication. He was born with anophthalmia (missing eyes), a cleft lip and palate which has not been corrected, scoliosis, and hypopituitarism. It was not expected that NR would survive and he was baptised on day one of his life by a Greek Orthodox priest who is his Godfather. Mr and Mrs R are devout Orthodox Christians.

2. NR has suffered from gastro-oesophageal reflux (and has not undergone surgery for that), gut dysmotility, recurrent lower respiratory tract infections, aspiration pneumonia, ventriculitis, mastoiditis, pancreatic pseudocysts, recurrent deep vein thromboses, chronic respiratory failure, and feeding intolerance. His burdens are many but from September 2020 to March 2023 he was cared for at home with additional professional nursing care and many hospital visits and admissions. On 18 March 2023 he was admitted to King's College Hospital (KCH) after transfer from the Evelina Hospital requiring intubation and ventilation for respiratory symptoms. He was extubated on 30 March but required re-intubation on 15 June until 3 July. On 13 October 2023 NR suffered two cardiac arrests since when he has remained intubated and on artificial ventilation. On 19 December 2023 he coughed out his ventilation tube but could not breathe unassisted and it was re-inserted. He is cared for on the paediatric Critical Care Unit at KCH. On 27 November and 6 December 2023 NR underwent insertion of stents of his pancreatic pseudocysts under general anaesthetic. It is proposed that he undergoes a further procedure to remove the stents in early February 2024 if he is sufficiently clinically stable to undergo the procedure.

3. On 6 December 2023 the Applicant Trust, responsible for KCH, applied to the court for three groups of declarations that it would be lawful to withhold certain medical treatment from NR in certain circumstances:

    i) In the event of a deterioration in his condition:

        a) Further inotropes

        b) Further escalation of ventilatory support

        c) Provision of extra-corporeal membrane oxygenation (ECMO)

        d) Haemofiltration.

    ii) In the event of a deterioration in NR's condition following successful extubation,

        a) Bag valve mask ventilation

        b) Endotracheal intubation

        c) Invasive ventilation.

iii) In the event of a deterioration in NR's condition leading to cardiac arrest, administering cardio-pulmonary resuscitation (CPR).

4. No application has been made for a declaration that it would be lawful to withdraw ventilation. I gave directions on 13 December, including permission to the parents to instruct an independent expert paediatric intensivist, Dr Nadel. On their behalf, in advance of this hearing in January 2024, Miss Gollop KC and Mr Jackson on behalf of the parents applied to adjourn determination of the second group of declarations on the basis that they ought to be determined, if at all, only as and when extubation was proposed. The other parties ultimately agreed that I should not be asked to determine questions regarding re-intubation or ventilation after extubation at this hearing. It may be that a further hearing will be required to determine such issues and directions will be given accordingly.

5. The parties have also agreed to ceilings of care as reflected in the declarations sought at 3(i) (a) to (d) above. There is a minor remaining dispute about the provision of inotropes which I shall address in this judgment but the central remaining disagreement is as to the third proposed declaration, namely whether, in the event of a cardiac arrest, CPR should be administered. The Trust, supported by its clinicians, by clinicians from other NHS Trusts from whom it has sought second opinions, by Dr Nadel, and by the Guardian, submits that the declaration should be made. The parents oppose it but also contend that I should not make a decision about that declaration separately from determinations about whether continued ventilation is in NR's best interests.

6. Whilst the proposed declaration regarding CPR would apply whether or not extubation had taken place, it seems to me that my primary focus should be on the present circumstances, i.e. with NR receiving ventilatory support, in particular because extubation will not take place without either agreement of the clinicians and parents, or a further court order. As and when determinations are made as to extubation, in particular if the extubation were considered likely to result in NR's death, then the question of whether resuscitation using CPR would have to be revisited in those changed circumstances. Accordingly, I proceed on the basis that the issue of administering CPR after a cardiac arrest arises in the context of NR continuing to be intubated and ventilated and that no party is submitting that it is contrary to NR's best interests to continue to receive life sustaining ventilatory support.

7. It is important that I reassure the parents that although some of the evidence put before me would suggest that clinicians at the Applicant Trust believe that it is contrary to NR's best interests to receive life sustaining treatment, I am dealing only with a discrete issue of whether it is in his best interests not to be administered CPR in the event of a cardiac arrest. I assume, for the purposes of that decision that it is not contrary to his best interests to continue with life sustaining treatment in the absence of a cardiac arrest.

8. Following lengthy discussions outside court, the parties agreed that I did not need to receive any oral evidence. I have read the written evidence of Dr A, High Dependency Consultant at the Trust, Dr B, Consultant Paediatric Neurologist, Mr C, Consultant Paediatric Surgeon, and Professor D, Consultant Paediatric Intensivist, all employed by the Applicant Trust. I have read second opinions from Dr E, Consultant Paediatric Intensivist and Ms F, Consultant Paediatric Surgeon. I have read the evidence from Dr Nadel, Consultant Paediatric Intensivist, instructed by the parents. I have also read statements Mr and Mrs R and a letter to the court from NR's Godfather, a Greek

Orthodox priest. I have also had the benefit of the written report of the Children's Guardian. After lengthy discussions at court, I was provided with a document setting out the views of Professor D and Dr Nadel on a number of questions from the parties. I received oral submissions from Counsel.

Legal Principles

9. In many cases where decisions must be made about life sustaining treatment of a young child, there is no need for court intervention: the treating clinicians and family will come to an agreement. Here, there is no agreement on all the provision of treatment I have identified, notwithstanding discussion and mediation. Accordingly, the parties ask the court to make determinations. The key legal principles applicable to the determination of whether life sustaining treatment, here increased ventilatory support and CPR, may lawfully be withheld from a patient, are those that apply also to cases involving the proposed withdrawal of life sustaining treatment. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591. at [22] Baroness Hale said,

> "… the focus is on whether it is in the patient's best interests to give the treatment, rather than on 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 that 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."

And at [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 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."

10. Key principles from authorities including *In Re J* (A Minor) (Wardship: Medical Treatment) [1001] Fam 33, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *An NHS Trust v MB* [2006] EWHC 507, [2006] 2 FLR 319 at [16] , and *Yates and Gard v Great*

Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410 as they apply to a decision whether to declare lawful the withholding or withdrawal of life sustaining treatment, can be summarised briefly as follows:

i) The child's best interests are the court's paramount consideration and must be viewed from the assumed point of view of the child patient.

ii) The term "best interests" is used in its widest sense and is not limited to medical considerations.

iii) There is a strong presumption in favour of taking all steps to preserve life but it may be displaced if other considerations outweigh it.

iv) The views of parents, clinicians, and others caring for the child should be taken into account, but no one person's views, including those of a parent, are decisive.

11. The court must apply these principles to the particular facts of the case. Evidence as to the child's condition, the nature of any proposed treatment, and the prediction of outcomes will form part of the basis of judgements as to what is in their best interests. It is important to note that these principles and the relevant factors in assessing what is in a child's best interests apply to all children, whether disabled or without disability. Application of these principles will afford proper recognition to the child's and family's Convention rights. As I sought to explain in *Guy's & St Thomas's NHS Foundation Trust* [2022] EWHC 2422 (Fam), the court recognises and respects the child's dignity by conscientiously applying the established legal principles and should not be drawn into making a decision that accords with the court's own concept of dignity. In the present case the parents' religious convictions and their relationship with NR lead them to adopt a different concept of his dignity than might be held by a disinterested observer.

Professional Guidance

12. I have regard to the Royal College of Paediatrics and Child Health's (RCPCH) document, "*Making decisions to limit treatment in life threatening conditions in children: a framework for practice*" in which it is stated,

> "It is ethical to withhold or withdraw life sustaining treatment if:
>
> a) Such treatment would be medically inappropriate and could not achieve its intended purpose of preserving life or restoring health
>
> b) Treatment would no longer be in the best interests of the child in that its burdens outweigh the benefits
>
> c) A competent child refuses to consent to the starting of treatment or requests that it be discontinued."

The guidance also assists in relation to CPR:

> "The purpose of CPR is to attempt to restart the heart of breathing and restore circulation after a cardio-respiratory arrest. It often includes invasive procedures, for example, obtaining access to the child's airway and circulation. Its success rate is dependent on circumstance but generally lower than is commonly perceived by the general public. Both CPR< and the physiological process leading up to a cardio-respiratory arrest, may have both harmful side effects and adverse consequences, for example hypoxic brain damage and poor neurological outcomes. If it is unsuccessful it may mean that death occurs in a traumatic and undignified manner and often in the absence of parents."
>
> … an attempt to provide CPR is inappropriate if:
>
> - It is unlikely to be successful …
>
> - There is a limitation of treatment agreement or other end-of-life care plan that excludes its use
>
> - Even if successful it is likely to produce more burdens than benefits."

As the RCPCH guidance notes, "clinicians cannot be compelled to provide treatment they feel not in the child's best interests." Ms Khalique KC confirmed that no clinician at the Trust considers it would be in NR's best interests to be given CPR in the event of a cardiac arrest. Accordingly, if I make the declaration sought, it will allow clinicians to know that not to administer CPR after an arrest would be lawful, but if I make no such declaration then it will be a matter of clinical judgment whether to administer CPR in those circumstances. Likewise, subject to the agreed ceilings of treatment at paragraph 3(i) above it will be a matter of clinical judgment as to whether the administration of CPR in any other circumstances is in NR's best interests.

13. Miss Gollop KC submitted that I should postpone any determination of the application for a declaration regarding CPR in the event of a cardiac arrest. The parents would regard it as one of a "thousand cuts" – it would signal to them that the court was minded to accede to a later application for a declaration that it would be lawful to withdraw all life sustaining treatment, including ventilation. That concern is not warranted. The declaration now sought is confined to the question of withholding CPR *in the event of a cardiac arrest*. Any determination about withdrawing life sustaining treatment even in the absence of an acute event such as an arrest, would involve different considerations and will follow the submission of more evidence, including from the parents. It is likely that I will be the judge hearing any further applications and I keep an open mind. The evidence shows that it is foreseeable that NR could suffer a cardiac arrest at any time. He suffered two in quick succession in October 2023 and his physiological reserves have diminished since that time. It is unlikely that the court will make further determinations about life sustaining treatment for some weeks and, in my judgement, parents and clinicians who cannot agree on NR's best interests require clarity as to what is lawful in the specific and circumstances of a further cardiac arrest.

Whilst making no order at this hearing in relation to CPR following cardiac arrest would leave the matter to the judgment of the clinicians, the clinicians clearly wish to know that if their decision was not to resuscitate, it would be lawful. Alternatively, a decision now that the declaration should not be made because the court considers it would be in NR's best interests to be administered CPR would be likely to influence the clinicians' treatment of NR in the event of an arrest. My case management powers, applying the overriding objective, and ensuring fairness to all parties, allow me to decide whether to determine the issue before me now or to postpone it to a later hearing. In my judgment it is in the interests of justice, the parents, the clinicians and NR to make a decision now on the application regarding CPR following a cardiac arrest.

NR's condition and prognosis

14. There is a large measure of agreement as to NR's current condition. He requires mechanical ventilation and cannot presently be weaned off ventilation, albeit he has been weaned to lower settings since October 2023. There is x-ray evidence of interstitial lung disease. Having required inotropic support to maintain normal blood pressure following his cardiac arrests in October 2023 until 20 November 2023, he no longer requires the same. NR has suffered with a distended abdomen causing him discomfort. He underwent surgery including draining of fluid from a pseudocyst and stent insertion in November 2023 and further insertion of two stents on 6 December 2023. He has struggled to tolerate feeds via a J-Peg tube and is currently on total parenteral nutrition (TPN). At the request of his parents, trials of enteral feeding via his J-Peg are not currently being attempted. The plan is for the stents to be removed in early February 2024 if NR is sufficiently clinically stable to allow for the procedure to be performed safely. Any consideration of whether he can manage without intubation will be deferred until he has recovered from that procedure. NR has suffered multiple episodes of sepsis to which he remains prone although his inflammatory markers are currently low. He has missing Eustachian tubes and is more prone to ear infection as a result. In July 2023, he suffered mastoiditis requiring drainage of pus. He went on later to suffer from ventriculitis leading to destruction and thinning of bones of his skull. NR suffers with self limiting seizures which "break through" his medication.

15. NR cannot communicate verbally and the severity of his condition raises the question of his awareness and his ability to experience pain and pleasure. There is ample, troubling evidence that NR can feel pain. This is monitored by staff at KCH using a FLACC score (face, legs, activity, cry, and consolability). The maximum score using that tool is 10 but a score of 5 or more indicates experience of significant pain. NR has frequently scored 5 but he has been more settled of late: since 23 December 2023 his score has been zero save on two days, once when he scored 1 and another when he scored 3. He has not required intravenous morphine since 30 December 2023 and has had no oral morphine since 10 January 2024.

16. Ms S, the Children's Guardian, has reported on seeing NR apparently consoled by his mother's touch. I have seen video of NR apparently taking pleasure from his mother making pleasant noises to him and moving him about but that was from a time when NR was cared for at home. In her first statement, made on behalf of her and her husband, Mrs R stated,

> "NR does respond to us, he clearly relaxes when we touch him, cuddle and or massage him. Equally when he is given injections he will feel pain, and react to it, by a little cry, and moves a bit, he clearly notices injection, and feels the little scratch when they happen.
>
> "We believe that his life is meaningful to him, to us, to his wider family, his Godfather, and other people who have formed a connection with him, such as his carers from home. When we are with him and hold him, we experience a connection with him and deep love. We believe this is connection and love is two way not just one way from us to him. We know that he knows us and responds to us. We have experienced him enjoying activities and know that he is capable of enjoyment. We can tell when he is in pain and we can tell when he is relaxed, enjoying something and happy. Probably none of his positive feelings show up on tests of cerebral activity but this is our experience of being with NR."

17. Ms S's observations corroborate the parents' evidence that NR can be consoled by them and the Trust does not seek to contest it. The parents, through Counsel, told me that they have more evidence they would like to give the court about NR's responsiveness to their touch and their voices. I accept, for the purposes of this hearing, that NR can be consoled by his parents and that he can still experience some pleasure from his contact with them. Sadly, the other side of that coin, as the parents accept, is that he can experience pain also, and can be distressed by interventions he can feel but not understand.

18. A CT scan dated September 2023 shows "a loss of the normal cortical grey-white matter differentiation … affecting the majority of NR's cortex … consistent with the expected evolution of irreversible brain injury that will evolve to encephalomalacia" meaning that loss of brain tissue will occur. The prognosis for NR is bleak but life expectancy cannot be predicted with any accuracy. Dr Nadel's view is that "his life expectancy is perhaps weeks to months if he continues to be intubated and days to weeks if he is extubated. However, these estimates are notoriously unreliable."

19. There is no prospect of NR recovering to the extent that he will have anything more than a very limited awareness of his surroundings. He can experience pleasure and feel pain. I accept that he can sense and be consoled by his parents' touch and voices. There is no treatment that can lead to recovery from his brain malformation. Treatment can be given to try to relieve his symptoms, minimise his discomfort and pain, and to try to keep him alive. However, although currently stable, he has suffered long periods of painful and distressing symptoms, and he could deteriorate suddenly, or more gradually, and die even with all attempts being made to keep him alive.

20. Professor D and Dr Nadel are largely agreed on the balance of clinical risks and benefits of administering inotropes to NR. Inotropes include adrenaline and noradrenaline. They may be used to try to restore falling blood pressure. They agree that in relation to a specific planned procedure that has been provided to NR that may have caused his blood pressure to change. Therefore, intraoperatively and for six hours post-operatively after

the stent removal procedure planned for early February 2024, or a procedure such as endoscopy or J-Peg replacement, inotrope administration should be used and, indeed, other ceilings of care should be suspended. Professor D's view is that otherwise inotropes should not be administered, only boluses of fluid, whereas Dr Nadel's opinion, as expressed in his responses to questions and then refined in the note of the professionals' meeting, is that if blood pressure changes as a consequence of medication, such as sedation, then subject to a cap of 0.5 mcg/kg/minute for adrenaline/noradrenaline, inotropes should be administered. If NR did not respond to 20ml/kg fluids and inotropes at that level, he should be regarded as "refractory to treatment". He has set out his reasoning in a very detailed initial report.

Cardio-Pulmonary Resuscitation

21. Dr Nadel has provided considerable detail of what CPR would involve should it be administered to NR following a cardiac arrest. Much depends on whether initial resuscitation attempts are successful, but in NR's case it is likely that a decision would be made to extubate and then ventilate by a self-inflating bag, or leave his ventilation tube in place. He would require chest compressions, use of a defibrillator if NR were displaying "shockable rhythms", and, in the absence of any ceilings of treatment, administration of inotropes. Reversible causes of the cardiac arrest would have to be reversed if possible. Dr Nadel and Professor D have agreed that NR's bones are brittle and that there would be a risk of rib fractures, but the parents do not accept that there is any objective evidence of low bone density or "brittle" bones. The parents have agreed that intraosseous administration would not be in NR's best interests. This is a means of obtaining vascular access by insertion of a needle into bone.

22. There is unanimity amongst the treating clinicians and those from other NHS Trusts who have provided second opinions that CPR should not be given to NR in the event that he suffers a further cardiac arrest because it would be contrary to his best interests. Dr Nadel's opinion as to the proposed declaration is,

> "In my opinion, in the event of a deterioration in NR's medical condition which leads to a cardiac arrest it would be inappropriate to commence CPR."

Parental Views

23. Mr and Mrs R witnessed NR being administered CPR twice on 13 October 2023. They know what would be involved if it were to be administered again. They oppose the declaration sought. To them, it would be unacceptable to deprive NR of the chance to recover from a cardiac arrest, just as he recovered, in October 2023. They believe that it would be in his best interests to administer CPR in the event of a cardiac arrest even if CPR would be unlikely to succeed and even if NR's last living minutes were spent in the hands of clinicians administering CPR.

24. Mr and Mrs R have stressed the importance of their religion, into which NR has been baptised:

> "We are Eastern Orthodox Christians and religion plays an important part in our life. The last few years have not been the easiest: the long wait until we found out we were finally going to have a child (13 years), the moment we found out about his diagnosis, then learning how to look after a child at home, especially one with very complex needs, the challenges with the current hospitalisation, and now, this court case. These are all factors which would make anyone very weak and physically and mentally drained, especially when there is no family support network around to rely upon. It feels that we have been fighting since before he was born for NR to be given a chance to live. Knowing God and keeping our faith has helped us a lot to get through all these challenges."

Their wish is for NR to be given as long a life as the clinicians can provide for him and as God will allow. Their priest, NR's Godfather, has written to the court explaining how NR's "little life" continues to enrich others, in particular his parents. The fact that he is disabled should not lead to him being deprived of care which might give him another chance of returning home. Mr and Mrs R have stated that what they really want is to be able to take NR back home.

25. The parents' agreement to certain ceilings of care and to intraosseous access not being in NR's best interests (it is a very painful procedure) indicates that they do not believe that all interventions should be attempted to preserve NR's life "at all costs". However they do not agree that another cardiac arrest should be regarded as the time to end further attempts.

Discussion and Conclusions

26. I remind myself that the issues I now have to determine are relatively narrow. I am not being asked to decide whether it would be lawful and in NR's best interests to withdraw life sustaining treatment. Decisions about the possibility of extubating whether with the expectation that he would soon die, or with a view to allowing him to live, perhaps out of hospital, without intubation for as long as possible, have not yet been made. He remains intubated and supported in the Critical Care Unit. He is currently relatively stable but his underlying conditions are irreversible and his condition has deteriorated since his cardiac arrests in October 2023. His life expectancy is very limited.

27. There is a narrow dispute between Dr Nadel and Professor D regarding the use of inotropes outside a planned procedure. Professor D says they should not be administered at all, Dr Nadel says they should but only in relation to falling blood pressure caused as a side-effect of medication and subject to the caps set out above. I am persuaded by Dr Nadel's reasoning and accept his advice that low dose inotropes to correct hypotension related to the administration of drugs would not have "adverse effects" whereas higher doses "may cause harm". I am satisfied that the modest steps he suggests in response to hypotension related to drugs would not be too burdensome for NR but would have potential benefit of preserving his life. Accordingly, whilst a

declaration should be made that it would be lawful not to administer inotropes, there should be an express exception in the terms advised by Dr Nadel.

28. There has been no application for a declaration that it would be lawful to withdraw life sustaining treatment including ventilation. The parents and Guardian have not had to respond to such an application. Accordingly, it would be wrong to determine that it was contrary to NR's best interests to receive CPR solely on the basis that it would not be in his best interests to continue to live with his current collection of conditions, limitations, and symptoms. If CPR were guaranteed to be successful, did not involve any harm to NR and would restore him to his current condition then, given the presumption that all steps should be taken to preserve life, I would conclude that the administration of CPR following cardiac arrest was in his best interests.

29. NR's current condition is relevant but my focus is on a number of specific questions that arise in relation to the provision of CPR following cardiac arrest. First, would CPR itself cause pain, distress, or harm whilst it is being administered? Second, is it true of NR's case, as described in the RCPCH guidance in relation to CPR, that "both CPR, and the physiological process leading to cardio-respiratory arrest, may have both harmful side effects and adverse consequences, for example hypoxic brain damage and poor neurological outcomes"? I have to consider the likelihood that after cardiac arrest and successful CPR, NR would be worse off than he is now. Third, what are the prospects of CPR being successful in resuscitating NR? Fourth, given that there is no guarantee that CPR would be successful, what would be the circumstances of NR's death if CPR were given but failed, and how would that compare with the circumstances of his death if no CPR were given following a cardiac arrest?

30. CPR following the cardiac arrest of an intubated and ventilated child patient would be liable to involve a number of procedures and interventions as set out above. There can be no doubt that these interventions would be burdensome for him. He would undergo chest compressions and he may suffer injury such as cracked ribs. He might require defibrillation. He would be administered inotropes and receive other interventions designed to correct the cause of the arrest. The process of CPR has been described by Dr Nadel as "traumatic". Professor D describes it as being "distressing" and "painful" for NR.

31. NR's neurological function is very limited but he may well suffer from further insult to his brain following further cardiac arrest (if resuscitation were successful). Therefore, if he survived a cardiac arrest he might well have to suffer the additional burden of further brain damage. Care after successful CPR would be burdensome to NR. Professor Deep states that "the burden of post-cardiac arrest care would outweigh the benefit." Again, I caution myself that I have not received full evidence or any submissions in relation to the balance of burdens and benefits of maintaining NR's current condition, but the evidence I have is that post-cardiac arrest care, after CPR, would add to the burdens already suffered by NR.

32. Dr Nadel has been clear about the prospects of CPR following cardiac arrest being successful. He has compared NR's position now with that when he suffered cardiac arrests in October 2023:

> " …in my opinion he [is] in a completely different situation now (3 months later) than he was then. He has been ventilated for 3

> months, with episodes of sepsis, surgery, and inadequate nutrition.
>
> As stated in my report of 5th January 2024: "While it is clear that NR survived these events in October, because of the nature of his underlying conditions and his other complications (such as the intra-abdominal complications), in my opinion, if he were to suffer a further cardiac arrest on the balance of probabilities he would be unlikely to survive".

33. NR's parents are aware that if CPR were performed they would have to step back to allow the clinicians to administer compressions, shocks and other measures. If it were unsuccessful, as Dr Nadel says is likely, then during NR's last living minutes he will have been surrounded by clinicians compressing his chest and administering other interventions, suffering pain and distress as they attempted to resuscitate him, rather than, as is potentially the alternative, more peacefully passing away in the arms of his parents. However, Mr and Mr R would still prefer that all was done to try to resuscitate NR even if he has a further cardiac arrest. Their idea of a "good death" may not coincide with the views of clinicians but I must take into account their strongly held views. As Mr Hadden for the Guardian reminded me, I have to examine NR's best interests from his point of view. He is not capable of forming an opinion or wish on this matter but were he able to do so, it is likely that he would want to avoid pain and distress but would also want to avoid anguish to his parents. Contrary to what many might expect, they maintain that it would cause them more anguish if NR died without CPR being attempted than in the traumatic circumstances of failed attempts to resuscitate him. My conclusion is that NR would wish to die in more peaceful circumstances rather than in the midst of the trauma of attempted CPR, but in assessing his best interests I take into account the parents' views and wishes and, on the facts before me, I do not consider this factor – the possible circumstances of death - as weighing heavily against a conclusion that CPR following cardiac arrest would be against NR's best interests.

34. I have taken full account of the parents' views about what is in NR's best interests, and also of their wishes. I have taken into account the view of the treating clinicians who, I am told and accept, are unanimous in their view that CPR following cardiac arrest would be contrary to NR's best interests.

35. I have also to contemplate the possibility that if CPR were successful, a further cardiac arrest might follow, as in October 2023. There is potential for CPR being required more than once, although that is unlikely given the evidence that CPR is unlikely to succeed.

36. The declaration sought would not direct clinicians to refuse to give CPR but would allow them to decide that CPR following cardiac arrest would not be in NR's best interests in the knowledge that such a decision had been declared lawful by the court. I have to consider the "no order" principle and whether any declaration is required in NR's best interests. As already noted, close scrutiny of the evidence and of NR's best interests in the widest sense, and application of the established legal principles, taking into account the views and wishes of the parents, affords appropriate respect of their and NR's Convention rights and respects NR's innate dignity as a human being.

37. CPR following cardiac arrest would be intended to preserve life but the presumption that all steps should be taken to preserve life is rebuttable. The RCPCH guidance at paragraph 3.2.3 states that an attempt to provide CPR is "inappropriate if … it is unlikely to be successful in restarting the heart of breathing because of the child's underlying condition". That is the position here. I place weight on the evidence of Dr Nadel, agreed by Professor D, that NR's depleted physiological resources and his general condition mean that he will probably die following any further cardiac arrest even if CPR is attempted. CPR would itself be burdensome for NR, causing "pain" and "distress". It is possible that his life would be preserved but also possible that in those circumstances he would have suffered further brain insult as a result of the cardiac arrest and/or resuscitation. On the balance of probabilities CPR would not successfully restore NR to his present state following a future cardiac arrest either because it did not preserve his life or because it did so, but his condition became even more parlous. Furthermore, if he survived he would suffer the additional burdens of post-cardiac arrest care. These matters, focusing as they do on the particular consequences and implications of administering CPR in the event of a cardiac arrest, are of particular importance in reaching a conclusion on this application.

38. In weighing the evidence and considering NR's best interests in the widest sense, I conclude that it is not in NR's best interests to be administered CPR following a cardiac arrest. This conclusion has been reached by the clinicians treating NR, the clinicians from other NHS Trusts who gave second opinions, Dr Nadel, who was instructed as an independent expert by the parents, and by the Guardian. It is a conclusion that is in accordance with the RCPCH guidance. I am not bound to accept their opinions or to follow that guidance and I have regard to the wide range of factors affecting NR's best interests. But, for the reasons given, my conclusion is the same and I shall make a declaration that it would be lawful not to administer CPR in the event that NR suffers a cardiac arrest. That declaration will provide clarity to the parents and clinicians alike pending any further agreements or determinations about NR's continued care including intubation and ventilation.

39. Mr and Mrs R will find it hard to accept this decision but I want to record that their devotion to NR has made a deep impression on the court and on those involved in caring for their son at the hospital. Sadly, litigation can serve to drive parties apart rather than to bring them together, but the evidence is that the parents have sought to work collaboratively with healthcare professionals. They entered into mediation with the Trust at the end of 2023 but unfortunately that did not resolve the differences between the parties. Nevertheless, dialogue has helped to narrow the issues before the court at this hearing. Mr and Mrs R have attended court and have been visibly anxious during the hearing, having to listen to submissions about the life of their adored son. I thank them for the way they have conducted themselves. Whatever decisions are required to be made in the future, they should know that the decisions made now do not prejudice any further hearings and that the court will always be guided by the evidence and the legal principles set out in this judgment.