Neutral Citation Number: [2024] EWHC 2400 (Fam)

Case No: FD2300605

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Date: 18 September 2024

Before :

MR JUSTICE POOLE

- -

Re NR (A Child: Ceilings of Treatment after Survival of Withdrawal of Life Sustaining Treatment)

Between:

(1) MRS R
(2) MR R

Applicants

- and -

(1) KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

(2) NR (By his Children's Guardian)

Respondents

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- -

Katie Gollop KC and Myles Jackson (instructed by Scott Moncrieff & Associates Ltd) for the **First and Second Applicants**
Bridget Dolan KC (instructed by Hill Dickinson LLP) for the **First Respondent**

Victoria Butler-Cole KC (instructed by Cafcass Legal Services on behalf of the Children's Guardian) for the **Second Respondent**

Hearing dates: 17-18 September 2024

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JUDGMENT

This judgment was delivered in private and a reporting restrictions order is in force. The reporting restrictions order is available on request from the RCJ Press Office. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment, the anonymity of the children and members of their family and of the treating clinicians anonymised in the judgment must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Poole :

Introduction

1. NR is a remarkable young boy. He was born with severe brain malformation and has suffered from significant medical challenges throughout his life. In October 2023, aged 3 and having already been treated as an in-patient for several months, he had two cardiac arrests requiring cardiopulmonary resuscitation ("CPR") followed by mechanical ventilation and total parental nutrition ("TPN") on a paediatric critical care unit to sustain his life. In April this year, after six months of such treatment and with clear evidence that there was no prospect of any recovery, I authorised the withdrawal of life sustaining invasive ventilation in the expectation, shared by all the medical witnesses who gave evidence, including an expert instructed by NR's parents, that he would die shortly thereafter.

2. Over four months after extubation, not only is NR still alive but he is now living at home. He is breathing for himself. He is fully enterally fed. He is urinating normally having previously had an indwelling urinary catheter. He has confounded all medical expectations and his case underlines the maxim that "medicine is a science of uncertainty and an art of probability." (Sir William Osler, 1849-1919).

3. Whilst NR's survival and progress are an unexpected gift to his parents, they feel "completely traumatised by everything that has happened." They have shown unconditional love and devotion to NR. They opposed the Trust's application to withdraw invasive ventilation because they believed that it was wrong to take a step that would bring about the end of his life. They have deep religious faith and they felt that NR had a subjective experience of life that was valuable to him as well as to those who love him. They believe that their views about NR were vindicated and they continue to believe that the Trust does not truly value NR's life. In the light of my decision in April 2024, Mr and Mrs R had to plan for their son's death. They feel confused about the advice they were then given and how NR has managed to defy all medical expectations. They are grateful to the NHS but they have lost their trust in the First Respondent. They now apply for the removal of the permitted ceilings of treatment which I authorised in January 2024. The Guardian supports that application. The Trust agrees to some changes to NR's care plan but not the discharge of all the authorisations.

4. I must record that I do not accept that the healthcare professionals and others at the Trust do not value NR's life. Their skill and care has kept him alive against the odds. They have always wanted what was best for him but their views about what that entails for NR's treatment and care continue to conflict with the views of Mr and Mrs R.

5. NR's case is highly unusual and raises some challenging questions for the court which must be addressed openly and objectively. Counsel could not point to any reported case in which a child has survived for months after the withdrawal of life sustaining treatment following a Court decision.

6. This is my third judgment in NR's case. The first was *Re NR (A child: Withholding CPR)* [2024] EWHC 61 (Fam), the second Re *NR (A child: Withdrawal of Life Sustaining Treatment)* [2024] EWHC 910 (Fam). The first judgment, given on 17

January 2024, explained the order permitting the Trust responsible for NR's in-patient care to withhold certain treatments from NR – so-called 'ceilings of treatment'. They were:

> "A. Group 1
>
> In the event of a deterioration in NR's condition, it is lawful and in his best interests for the following medical treatment to be withheld:
>
> i. Further inotropes;
>
> ii. Further escalation of ventilatory support;
>
> iii. Provision of extracorporeal membrane oxygenation ("ECMO");
>
> iv. Haemofiltration;
>
> B. Group 3
>
> In the event of a cardiac arrest, it is lawful and in his best interests not to administer cardio-pulmonary resuscitation.
>
> 3. The above ceilings of care in relation to the provision of CPR and administering of inotropes will be suspended during any operative procedure (intra-operatively and 6 hours post-operatively) or as a consequence of medication administered which lowers NR's blood pressure and the total maximum dosage of inotropes shall be limited to 0.5micrograms/kg/minute."

7. The Trust then applied for a declaration that it was lawful and in his best interests, to withdraw life sustaining invasive ventilation. The application was supported by the Guardian but opposed by NR's parents.

8. In my second judgment, given after a hearing in April 2024, I set out the well-established principles that the Court is bound to apply when considering whether a child's life sustaining treatment should be continued or withdrawn. Four fundamental principles are:

   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.

I scrutinised the medical and other evidence provided to the court and concluded:

> "[46] Standing back and weighing all the benefits and burdens to NR from continued treatment, I am quite sure that the burdens far outweigh the benefits. The burdens both of NR's conditions and symptoms, and of the invasive treatments, are many and they are heavy. They include the insertion of the endotracheal tube and invasive ventilation, frequent suctioning, total parental nutrition, blood samples being taken, repeated sepsis and episodes of septic shock, osteopenia leading to a femoral fracture and vulnerability to further fractures, and seizures (albeit currently relatively well controlled). Even now that he is relatively stable, and has very limited awareness, he still sometimes becomes visibly distressed or in pain. NR cannot enjoy any of the pleasures of being a four year old child save for being able to be soothed when in distress by his parents. Previously he was able, subject to his severe disabilities, to live at home with his parents, to go out of the house, to smile when cuddled. Now his life is grossly diminished and full of burdens."

9. I recorded in my judgment that it was expected that upon withdrawal of mechanical ventilation, NR would die within a short time. Although there were some differences in the degree of confidence with which prognoses were expressed, there was a consensus that after extubation, NR would be likely to die within a short time. Dr Nadel, the expert relied upon by NR's parents, expressed this in terms of days to weeks, but he was the most optimistic. I have checked my notes of the oral evidence of Dr F who had provided an independent second opinion to the Trust. When asked how long NR would survive after extubation, he replied: "Probably hours, sometimes children survive for days."

10. In my judgment I said at paragraph 19:

> "The evidence before me is that it is unlikely that NR will reach the point where he could be successfully extubated without the need for re-intubation to sustain life. Dr F and Dr C concurred that caring for NR with non-invasive ventilation at home was not feasible. Dr Nadel has written that it is unlikely that NR could tolerate non-invasive ventilation for a prolonged period. Furthermore, NR is not a child who could be managed on TPN at home. Hence, the medical evidence is that there is no realistic prospect of NR being able to return home for care over weeks or months. If he remains in his current, relatively stable,

> state without intervening sepsis or other complications then the evidence of Dr D, supported by Dr C and Dr F, is that it would be feasible to transfer him home for the purpose of extubation at home, whereupon he would be expected to survive only for a few hours or at most for a few days. Otherwise, he will die in a critical care unit in hospital, on invasive ventilation, probably within the next six months. His underlying conditions are not going to improve with treatment."

11. Dr C was a consultant paediatric intensivist at the (then) applicant Trust, Dr D was a paediatric palliative care consultant from a different trust, and Dr F was a consultant intensivist from a third NHS trust.

12. The evidence persuaded me that there was virtually no prospect of NR being weaned off the ventilator to the point of extubation (which was the evidence of Dr F and Dr C). So-called "one-way extubation" was possible but there was no realistic prospect of NR transferring to non-invasive ventilation for a prolonged period. The evidence also established to my satisfaction that there was virtually no prospect of NR moving to fully enteral feeding. At paragraph 43 I said that the evidence was that NR would never live at home.

13. I sanctioned the withdrawal of invasive ventilation and also declared, "it is in the best interests of NR that he is not resuscitated in the event of cardiac or respiratory arrest." That declaration was closely associated with the permission to extubate NR and the strong expectation that he would die shortly after extubation.

14. Having anxiously reflected on the previous judgments, I am satisfied that the conclusions I reached were justified on the evidence provided but it is right to acknowledge that the expectations that NR could not be cared for at home and would not survive long after extubation have not been fulfilled.

15. Had I known that NR would survive extubation for this long and would progress so that he was no longer dependant on TPN, no longer required an indwelling urinary catheter, and would be cared for at home, I would have had less hesitation about authorising the withdrawal of invasive ventilation. It was a burdensome treatment without which, as is now known, he would survive for months at least and be able to live a better life. I decided that continuation of invasive ventilation was not justified even though I expected that NR would die shortly after such ventilation was withdrawn. As it has transpired, NR has been relieved of the burdens of invasive ventilation and has not only survived but has made progress and enjoyed relief from other interventions such as TPN and an indwelling catheter. If anything, extubation may have unlocked a number of beneficial consequences for him.

16. A decision to withdraw life sustaining treatment is not a decision to bring about the death of a patient, but a decision that the continuation of the treatment is not in their best interests. NR's survival and progress have shown that the withdrawal of invasive ventilation was indeed in his best interests. At the time, based on the prognoses

provided to the Court, I decided that ventilation should cease despite, not because of, the strong expectation that NR would die soon afterwards. I do not wish to minimise the emotional turmoil suffered by Mr and Mrs R and the continuing burdens that NR suffers because of his conditions, but it seems to me to be a wonderful surprise that NR has confounded expectations, that he no longer requires continuing invasive interventions and, in particular, that he has been able to return home to the loving care of his devoted parents.

17. Nevertheless, the evidence continues to show that NR's underlying conditions will not change. I have been provided with updated evidence from Dr C, Consultant Paediatric Intensivist, Dr F, and Dr D, Palliative Care Consultant. In addition I have received written evidence from medical professionals who did not give evidence at the previous hearings: Dr G, a Consultant Paediatric Intensivist at the Trust, Dr H, Paediatric Consultant at a different NHS Trust who has been responsible for the out-patient care of NR since his return home, and Dr J, Consultant Paediatric Respiratory Consultant at the Trust.

18. In late April/early May 2024 the paediatric team at the Trust tried to wean NR off ventilation but he had intermittent episodes of increased work of breathing with desaturation and hypercapnia (a build-up of carbon dioxide in his blood secondary to infection) requiring increases in ventilatory pressures. He was nevertheless transferred to a hospice, still on invasive ventilation and TPN. NR was extubated at the hospice on 8 May 2024. The palliative care team under Dr D gave full support. NR was able to breathe for himself. He required two courses of antibiotics when at the hospice for signs of a urinary infection but he was able to be transferred home, on enteral feeding (and no TPN), in early June 2024.

19. NR has been cared for at home now for about three and a half months. Dr H is the lead clinician from the NHS Truist (not Kings College Hospital NHS Foundation Trust) local to NR's family home. She has been overseeing care for NR since he has been at home. She informs the court that NR has a nasal cannula to deliver oxygen. His oxygen saturations are monitored and oxygen adjusted accordingly. He has saline nebulisers between once and three times a day. He is suctioned post nebuliser and sometimes in between using a deep suctioning technique. He has chest physiotherapy. He has a spontaneous cough. NR is now fed entirely via his J-PEG. He now has blended feeds. He regularly opens his bowels and does not suffer vomiting. It is not disputed that he now has no catheterisation of any kind. His seizures are controlled. He is able to travel by car to hospital appointments, he can sit in a chair, supported, and he can be taken outside to the park and elsewhere.

20. Dr H considered it necessary to insert into NR's notes

> "Parents have applied to court to have the ceilings of care reviewed and a date is set for 17th and 18th of September 2024.
>
> Pending that date, on discussion with [Dr J and Dr D] if NR presents to [the local hospital] we feel it would be reasonable to treat reversible causes, and offer ward based and HDU care here as necessary, including:
>
> IV fluids

PO/IV antibiotics

HFNC

NIV

Chest physio

The court order currently states not for CPR, and not for intubation and ventilation, and these should therefore not be undertaken without direction from STRS / PICU teams, or if / when agreed by the court.

Please do contact me directly if you need further clarification.'

21. Mrs R has provided a detailed, moving, and thought-provoking statement about NR's progress since the last hearing. She has included within it photographs showing NR smiling, attending church, in the park and surrounded by those who love and care for him. Mr and Mrs R understandably feel that their belief that NR could make progress and had more resources and awareness than medical professionals credited him with, was wrongly discounted. They consider that they know their son better than anyone and they have been proved right and the medical profession proved wrong.

> "Our basic point is that statistics don't help with NR. It would be more honest if doctors acknowledged that he is an individual that medical science doesn't really understand and isn't a good basis for predicting what this complicated little boy can do….
>
> NR survived when the doctors and nurses who looked after him for months thought he could not. He has a right to life. It seems to us his will to live is strong and his life is good. The orders that were made when King's believed he could never survive outside hospital and he had no quality of life in hospital are interfering with his right to life. They are absolutely damaging his family life and ours. NR has earned a new start and he deserves it."

22. The application before me is that of Mr and Mrs R who invite the court to discharge the extant declarations referred to at paragraphs 6 and 13 above. They say, firstly, that the declarations should no longer apply because of the significant change in circumstances. Ceilings of treatment which might have been considered appropriate when NR was in a critical care unit, dependent on invasive ventilation, are not appropriate when he is living at home unventilated. Secondly, the parents' perception is that the overall effect of the declarations leads healthcare professionals not to treat NR as actively as they might otherwise. Thirdly, there are so many possible changes and challenges ahead for NR, and so many uncertainties, that it is not possible to craft workable declarations. Indeed the court should not try to do so.

23. For the First Respondent Trust, Ms Dolan KC accepted during submissions that the Trust would not have applied for declarations from the Court permitting treatment to be withheld had NR been in his current condition and circumstances. She submitted that nevertheless there is a benefit to NR from keeping the current declarations in place to protect his best interests. Ms Dolan KC called Dr J who gave oral evidence. His view was that in the absence of any declarations permitting, for example, CPR to be withheld from NR, clinicians, particularly more junior professionals who might not have an intimate knowledge of NR's case would be likely to feel bound to take every possible step in active treatment thereby risking acting contrary to his best interests. He accepted that given that there was agreement amongst all parties that it would not be in NR's best interests to undergo ECMO or haemofiltration (Group 1 (iii) and (iv) of the January declaration of ceilings of treatment) there was no requirement for that declaration to remain in place. In those respects there was an understanding between parents and clinicians such that the Court's continuing declarations were not required. However, he did think that it would be helpful to clinicians for the Court expressly to permit the withholding of CPR, otherwise they would feel obliged to give it regardless of the consequences for NR. His view was, it seemed to me, strongly influenced by his own view that intensive care was contrary to NR's best interests. Dr J's view was that even knowing now that NR has been able to return home without ventilation or TPN, it would still have been in his best interests not to have been resuscitated in October 2023 because, to date, on balance he has suffered too many burdens. However, he accepted that if NR were to remain settled at home for another few months, that assessment might change.

24. Ms Dolan KC proposed that clarification be added to the existing declarations as follows:

> "- In the event that NR suffers a cardiac arrest it would not be in his best interests to administer cardio-pulmonary resuscitation and to withhold CPR would be lawful
>
> - In the event of a deterioration in NR's condition it is in NR's best interests not to receive inotropes and it is lawful to withhold the same.
>
> - The above ceilings of care in relation to the provision of CPR and inotropes should be suspended during any operative procedure (intra-operatively and six hours postoperatively) or as a consequence of medication administered which lowers NR's blood pressure and that the total maximum dosage of inotropes is limited to 0.5 micrograms/kg/minute.
>
> - *Further, the above declarations do not prevent any doctor or healthcare professional from providing CPR or inotropes to NR if in the view of the attending clinicians at the material time would be reasonable to do so in view of his prospects of recovery, and no aspect of this declaration limits, restricts or fetters the decision of clinical staff in anyway*." [Emphasis added].

25. The Guardian supports the parents' application to discharge the current declarations. She has taken great care to visit NR and his parents at home and to reflect on the changes in circumstances. She rightly submits that it is not for the Court to direct clinicians as to what treatment to give to a patient nor, in a private law case, to order that resources be allocated in a certain way. Ms Butler-Cole KC for the Guardian submitted that in a case such as this where NR's circumstances are not fully predictable and where the Trust accepts that new medical evidence at the relevant time may mean that any declaration granted is not in fact followed, the Court should exercise caution before making or continuing any declarations. Baroness Hale endorsed such caution in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. In *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR 3995, the Court of Appeal said:

> "117. We would, however, as a matter of practice counsel caution in making declarations involving seriously damaged or gravely ill children which are open-ended. In the same way that this court said in R (Burke) v General Medical Council (Official Solicitor intervening) [2005] 3 WLR 1132 that it is not the function of the court to be used as a general advice centre (see para 21 of this court's judgment), it is, in our view, not the function of the court to oversee the treatment plan for a gravely ill child. That function is for the doctors in consultation with the child's parents. Judges take decisions on the basis of particular factual substrata. The court's function is to make a particular decision on a particular issue.
>
> 118. As a general proposition, therefore, we have reservations about judges making open-ended declarations which they may have to revisit if circumstances change."

26. The four core principles set out at paragraph 8 above apply equally to the current issues before the court, and to decisions to withhold life sustaining treatment, just as they did to the decision to authorise the withdrawal of life-sustaining treatment. But the circumstances have materially changed since the declarations made in January and April 2024. NR continues to suffer the burdens of his condition and of some of the treatment and interventions he has to undergo. However, the burdens of his treatment are significantly reduced compared with those he suffered prior to extubation. There is also evidence that he is now able to derive pleasure from his life at home with his parents. There is evidence that he sometimes smiles. Previously, when the initial declarations were made in January 2024, he was suffering many more burdens from invasive treatment, he showed signs of distress, there was little to no evidence that he could derive pleasure from life, other than the consoling touch of his parents, and there was thought to be virtually no prospect of him enjoying any improvements. He was trapped in a critical care unit. Now he can be taken outside, for example to the park. He can enjoy the sun on his face and the feel of the wind in his hair. He is living in a loving home environment.

27. It remains unexplained how NR has managed to confound the expectations of all medical professionals who assessed him and treated him prior to his extubation on 8 May 2024. The opinions expressed to the Court that he would never be able to be cared for at home, would never be free from TPN, and would survive only a short time after extubation were, I accept, soundly based on the evidence available and the considerable experience of the witnesses giving those opinions. I have not seen anything to suggest that the opinions expressed were ill-founded, that relevant evidence was disregarded, or that investigations and clinical indicators were misinterpreted. It is simply the case that medicine is a "science of uncertainty". Medical predictions are an "art of probability" and sometimes the unexpected happens. It does not diminish the value of opinion evidence including prognoses, that they are based on probabilities and that unexpected outcomes may occur, but that possibility must be accounted for when making best interest decisions.

28. NR has defied the odds, but having done so the Court must consider the current evidence and determine whether continued or varied declarations permitting ceilings of treatment or the withholding of CPR are in NR's best interests. In my judgement they are not. My reasons are as follows:

    i) The declaration regarding CPR made in April 2024 was linked to the decision to permit the withdrawal of invasive ventilation and the strong expectation that NR would die shortly after extubation. Had CPR been given after extubation NR would have required re-intubation. Thus, having found that continued invasive ventilation was not in NR's best interests, it followed that neither was CPR. Now, however, NR has undergone extubation and can now breathe unassisted. Hence, a key justification for making the best interests declaration about CPR in April 2024 no longer applies.

    ii) The best interests decision to withdraw invasive ventilation was based on the evidence as to NR's condition and prognosis at that time. In January and again in April 2024 the evidence before the Court was that NR was highly unlikely ever to cease requiring a series of invasive treatments including invasive ventilation and TPN. CPR would not therefore lead to any better outcome for him. The best that could be hoped for was that CPR would allow him to return to the same, parlous state, requiring the same interventions. The benefits of CPR were therefore very difficult to identify. The position now is different. It would be wrong to gloss over the many adverse features of NR's underlying conditions as set out in the previous judgments, and the invasive treatments he still requires such as deep suctioning, but he is at home, not on TPN, without a catheter, and does not require ventilation. Whilst his underlying conditions have not changed, the need for invasive treatment has changed quite significantly. Whilst Dr J told the Court, and I accept, that following any administration of CPR in the future it is very likely NR would require invasive ventilation, it cannot be said that NR could not then ultimately recover to his present baseline state. He has done that once already. NR has recovered after his previous cardiac arrests in October 2023, CPR, and invasive ventilation to his current state which, Dr J suggested, might even be a better state than he was in prior to the cardiac arrests when, as will be recalled, he was an in-patient. Hence, the balance of benefits and burdens associated with a decision to administer CPR has changed significantly since April 2024.

iii) It cannot now be predicted with any confidence when and in what precise circumstances a decision may have to be made whether to administer CPR to NR. In January and April 2024 the evidence was clear that any CPR would have to be given when NR was an in-patient, already on invasive ventilation. Now, a decision might have to be made whether to give CPR tomorrow, in six months' time, or never. It might have to be made when he is in the community or in hospital. His state at the time of requiring any CPR cannot be predicted with any certainty. The prognosis for him at the time of any such decision will depend on a number of factors which cannot be known to the Court now. In the circumstances, the Court cannot provide a detailed decision-making flow chart for clinicians to follow when deciding whether to administer CPR, because there are too many variables. In January and April 2024 there were many fewer variables and a clear declaration could be made with much more confidence as to the circumstances in which it would apply.

iv) Dr J expressed concern that if CPR were given in the future, then NR might find himself back on long term invasive ventilation on a PICU or critical care unit. That is a possibility but, without wishing to sound glib, decision making by clinicians and parents about continuing such life sustaining treatment would have to be made at that time in full knowledge of the circumstances and evidence at that time. Ultimately, the Court would stand ready to make determinations about the withdrawal of treatment if required to do so but it would proceed on the basis of the known factors and prognoses available at that time. It is quite a different matter to make an advance decision without knowing the circumstances in which NR may find himself and to declare it lawful not to give CPR.

v) The Trust itself accepts that circumstances might arise in which a clinician could believe it to be reasonable to administer CPR to NR. It has proposed including clarification that any declarations by the Court "do not prevent any doctor or healthcare professional from providing CPR or inotropes to NR if in the view of the attending clinicians at the material time [it] would be reasonable to do so." It seems to me that if there may be circumstances in which a clinician could consider it to be in NR's best interests to administer CPR – and therefore reasonable to do so - then it would be inappropriate for the court now to permit the withholding of CPR without identifying those circumstances in which it might be against his best interests to withhold it. Yet, as a matter of practicality, I cannot identify those circumstances in advance because there are too many uncertainties and variables. I bear in mind the Court of Appeal's warnings in *Wyatt* at paragraphs 117 and 118 (above).

vi) As conceded on its behalf, the Trust would not have applied for the declarations obtained in January and April 2024 had NR then been living the life he is now living. That being so, it seems to me that prima facie the declarations ought to be discharged. The Trust would not apply for them now, so why should they be maintained?

vii) The Trust suggests that discharging the extant declarations, or at least those made in January 2024, leaving no declarations in place, will be likely to lead to uncertainty on the part of clinicians and, as Dr J suggested in his evidence, a tendency by clinicians to over-treat for fear of legal repercussions if they were

to withhold treatment. The Trust's concern is that the very fact that the Court has discharged the declarations may signal that all possible care ought to be given. I believe this to overstate the case. Many clinicians making decisions about NR's care in the future will not have read all three judgments in this case or be aware of the changes in declarations. Those who have done so will know that by discharging the declarations the Court is not directing clinicians to give all active care whatever their view of NR's best interests. I acknowledge the difficult decisions that clinicians have to make in relation to seriously ill children, and the particular difficulties when relations with the parents of those children have become strained or there are wide differences in core beliefs between parents and clinicians. However, as the Court of Appeal said in *Wyatt* (above) relying on *R(Burke) v GMC* [2005] 3 WLR 1132, "it is not the function of the court to be used as a general advice centre." In my judgement, declarations about ceilings of treatment should only be made when they protect or enhance a child's best interests. They should be worded so as to provide clarity for clinicians but that is not their purpose.

viii) The parents express concern that when declarations as to ceilings of treatment have been in place, it has encouraged a default position or assumption that NR should be allowed to die. Whilst the January 2024 declarations may be permissive rather than directive, they set a tone, say the parents, which should no longer apply given the progress he has made. Dr J's evidence rather underlined that parental concern as does the fact that Dr H felt it necessary to add a note in clarification within NR's records (see paragraph 20 above).

29. For clinicians who may be faced with difficult decisions about CPR, there is professional guidance including the following from *Decisions Relating to Cardiopulmonary Resuscitation*, published jointly by the BMA, Resuscitation Council (UK) and the Royal College of Nursing:

> "Doctors cannot be required to provide treatment contrary to their professional judgement, but doctors should try to accommodate the child's and parents' wishes where there is genuine uncertainty about the young person's best interests."

Good communication, obtaining second opinions or the advice of an ethics committee, even mediation, will usually lead to an agreed way forward. In the case of a child, parental wishes will be of considerable importance to clinical decision making. If, however, clinicians consider that the parental wishes are clearly at odds with the best interests of the child then, when an accommodation cannot be achieved, the Court may be required to make "a particular decision on a particular issue" *Wyatt* (above) para. 117.

30. In the present case, for the reasons given, the future administration of CPR may or may not be in NR's best interests depending on all the factors that apply at the time when the need for CPR might arise. In contrast to the situation earlier this year, it is not now appropriate for the court to make a general declaration that it would be in NR's best interests to withhold CPR. Adding a series of caveats or clarifications will be likely to cause more confusion not greater clarity and would result in declarations

that in effect permit clinicians to use their judgement about providing CPR in NR's best interests. That is what they are obliged to do in any event.

31. Hence, the previous declarations permitting the withholding of CPR shall be discharged.

32. The other declarations about ceilings of treatment, should also be discharged. Firstly, some administration of inotropes and some ventilatory support (which would now be an escalation because he does not currently have any ventilation) might well be in his best interests depending on the circumstances. The parents agree that ECMO and haemofiltration should not be administered and therefore there is no continued need for the court's intervention on those matters. Nor do I understand those to be treatments that are likely to be immediately available to NR given his current circumstances and care at home.

33. For these reasons I shall discharge all the current declarations.

34. I should re-emphasise that it does not follow that clinicians should cease to think very carefully about NR's best interests. Clinicians must have regard to all the evidence and their professional obligations, local and national protocols, and ethical guidance. They must strive to work with the parents and give respect to their views but they are not bound to agree with the parental views of NR's best interests nor slavishly to comply with parental wishes. NR is their patient and they owe their professional duties to him. The Court stands ready to make particular decisions in a child's best interests when it is necessary to do so, but not to "oversee the treatment plan" (*Wyatt*, above) nor to set out detailed guidance for future clinical decision-making.

35. This case does not establish that the Court cannot rely on medical evidence as to the prognosis for a critically ill patient. It does show that medicine is a science of uncertainty. The Court has to deal with medical predictions and probabilities and such evidence is very valuable. A prediction should not be disregarded simply because it may prove to be wrong. However, confident predictions are sometimes confounded and the Court must be vigilant and humble in the face of apparent certainty.

36. I commend all the healthcare professionals who have treated and care for NR. I do not doubt for one moment their dedication to trying to improve his circumstances and to serve his best interests. I also pay tribute to his devoted parents who have dealt with such trying circumstances with fortitude and grace. They have a remarkable child. Mrs R has told the Court, "he has proved to everyone his ability, his strength, his determination, his will to live." I had the pleasure of visiting NR in hospital in April 2024 and it is a delight now to see photographs of him at home with his loving parents. I wish the family all the best for the future.