



Neutral Citation Number: [2024] EWHC 910 (Fam)

Case No: FD23P00605

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Date: 23 April 2024

Before:

MR JUSTICE POOLE

**Re NR (A Child: Withdrawal of Life Sustaining
Treatment)**

Between:

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

Applicant

- and -

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

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
Christopher Osborne (of Cafcass Legal Services on behalf of the Children's Guardian) for the
Third Respondent

Hearing dates: 10-12 April 2024

JUDGMENT

This judgment was delivered in private. 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 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. The Applicant Trust has applied for a declaration that it is lawful and in the best interests of NR, the four year old son of the First and Second Respondents, to withdraw invasive ventilation and to discontinue his life sustaining treatment. NR was born with severe disabilities and life-limiting health-conditions including significant brain malformation. These have resulted in many medical complications. I have detailed those conditions and NR's history in a previously published judgment, *Re NR (A child: Withholding CPR)* [2024] EWHC 61 (Fam). Since that judgment was given on 17 January 2024, NR has suffered further episodes of infection and septic shock. He continues to be supported by invasive ventilation, as has been the case since he suffered two cardiac arrests on 13 October 2023. He continues to be cared for on the paediatric critical care unit at King's College Hospital where he has been for just over one year.
2. The Trust originally applied for a declaration that it is in NR's best interests for ceilings of treatment to be included in his care plan. That was the application on which I previously gave judgment on 17 January 2024, when I permitted some ceilings of treatment to be imposed. On 22 February 2024 the Trust applied for a declaration regarding the withdrawal of life sustaining treatment.
3. The application is supported by NR's Guardian but opposed by his parents. I have heard oral evidence from three of the treating doctors and a matron at King's College Hospital. Using different anonymisation from that used in my previous judgment, they are Dr A, Consultant Paediatric Intensivist and NR's lead clinician since February 2024, Dr B, Consultant Paediatric Neurologist, Dr C, Consultant Paediatric Intensivist, and Matron E. I have also received written evidence from Dr D, a Paediatric Palliative Medical Consultant from a different London NHS Trust, from Dr F, a Consultant in Paediatric Intensive Care Medicine and Paediatric Critical Care Transport at a third London NHS Trust who gave a second opinion to the Applicant Trust, and from Dr Nadel, Consultant in Paediatric Intensive Care Medicine at a further London NHS Trust, instructed by the parents as an expert witness. I heard oral evidence from both Mr and Mrs R who gave evidence together. I have received evidence from the Guardian. I have had regard to the full bundle of written evidence including statements and medical records.
4. In January 2024 I listed the case for a final hearing for three days. Later, I directed the Trust's February application to be determined at this hearing, which began on 10 April 2024. At the outset of the hearing I heard the parents' application for an adjournment. They wished to have time to explore the possibility of NR being transferred to a hospital abroad. They accepted that the application was made late, some two days prior to the hearing, and without any evidence of any offer to admit NR or as to the mechanics of his transfer abroad. I was told that preliminary enquiries had ruled out transfer to a hospital in the country of Mr and Mrs R's birth, NR having dual nationality with the UK and that country. There remained the possibility of NR being accepted by a hospital in Italy. I had no evidence as to whether any hospital there would accept NR, what the costs would be and how they could be met, or how a

transfer would be managed. Mr and Mrs R wanted me to make the determination of their adjournment application before I heard any evidence. I refused the application at that stage but directed that (i) questions could be put to appropriate witnesses about the feasibility and risks of transferring NR to a hospital in Italy, and (ii) the parents could, if they wished, renew their adjournment application after the evidence at the listed three day hearing had been given but before my determination of the substantive application. I gave full reasons for that decision in an ex tempore judgment on 10 April 2024.

5. On 12 April 2024, the oral evidence having been heard, the parents renewed their application for an adjournment. Mr R had by then booked a flight to Rome departing on the morning of 13 April 2024 in order to meet a senior Consultant Paediatric Intensivist at a hospital associated with the Vatican. I was asked to adjourn for a few days in order for the parents to explore the possibility of transfer to a hospital in Italy before making my determination on the Trust's application. Again I refused the application and I refused an application for permission to appeal that case management decision. My reasons for proceeding to hearing submissions and making a determination on the Trust's application for a declaration in relation to the continuation of life sustaining treatment without an adjournment were:
 - i) I had received ample evidence, including expert evidence on instruction from the parents, on which I could make a determination as to whether it is in NR's best interests to continue to receive invasive ventilation and other life sustaining treatment.
 - ii) I had received good evidence as to the feasibility, risks and complications of transferring NR by road and air to a hospital in Italy. Dr F is very experienced in making assessments and managing transport of very unwell children both within the UK and internationally, including by fixed wing aircraft. His evidence on the feasibility of transporting NR to a hospital in Italy, and the risks and consequences to NR of doing so, was authoritative and I accept it in its entirety. He told the court that it was feasible to transport NR abroad but that he would have to be given paralysing medication in order to manage the risks associated with such a transfer. He would be taken by ambulance to an airport, flown to Italy and then transferred by road ambulance to the destination hospital. His parents would be able to travel with him. He would be accompanied by a specialist intensivist. There would be a low risk of no more than 1-2.5% of NR suffering accidental extubation during a journey to a hospital in Italy, and a similarly low risk of death in transit, but there would be an almost certain deterioration in his condition as a result of the transfer. That deterioration would probably be reversible on arrival at the destination hospital but that reversal could take days or weeks and there would be no guarantee that NR would return to his current baseline level. Hence, there would be significant additional burdens on NR from being transferred to a hospital in Italy.
 - iii) If I were to decide that invasive ventilation and life sustaining treatment was contrary to NR's best interests then it would be equally contrary to his best interests to receive such treatment in Italy as in England.
 - iv) If I were to decide that such treatment was in NR's best interests then, given the additional burdens to him of a transfer to Italy, there would need to be some benefit to him from a transfer in order for it to be considered to be in his

best interests to be transferred. No additional or different treatment has been identified as being potentially available in Italy. Miss Gollop KC for the parents persuasively argued that the regime in an Italian hospital associated with the Vatican would be more in line with the parents' values and views about the purpose of treating NR. However, my focus has to be on NR's best interests. If he were to continue to receive life sustaining treatment in any event, then there would be no discernible benefits of transferring him abroad to receive that treatment. As already noted, transfer would however impose additional burdens on him.

- v) An adjournment to allow for further evidence on a transfer to Italy would risk raising satellite issues, causing delay, requiring more evidence in response, and detracting from the court's focus on NR and his best interests. Every day is of significance for him.
6. I offered to visit NR in hospital during the hearing if that is what the parents wished and if I could do so without causing any disturbance to the care of NR or any other patients at the hospital. I reminded the parties that a visit was not for the purpose of gathering evidence. I visited NR on the afternoon of 11 April 2024 after I had heard evidence from the medical professionals but before the parents gave evidence. The Guardian attended with me and made a note which has been circulated to the parties. The court has a solemn responsibility in a case of this kind and I hope that it is considered respectful by the family for me to have visited NR. A visit also enables the judge to see the child's environment and some aspects of their care which have been described in court, which assists the judge's understanding. Furthermore, as was said on behalf of the parents, it helped them when giving their evidence after my visit to know that I had a mental picture of NR and was able to envisage some of the matters they wanted to tell me about.
7. With the assistance of the clinical personnel at the hospital, I visited the Paediatric Critical Care Unit. There was a two person limit on the numbers who could be at NR's bedside, so the parents were not present. The Unit accommodates both children who need intensive care and children with high dependency. NR has a bed by a window separated by dividers and curtains from beds on either side of him. The room is narrow and his bed space quite small. There is room for a single chair and some storage space beside the bed. He has machines on either side of him with the ventilator to his left and parenteral nutrition delivered into a central vein via his right arm. He was covered in a blanket up to his shoulders. His left arm lay on top of the blanket and over a cuddly toy. There were other soft toys in bags beside his bed. Some religious icons were arranged behind his pillow and there were children's bibles on the window sill. There were signs of the celebration of his recent fourth birthday. He appeared peaceful, as if asleep.

Evidence

8. There is a broad consensus amongst the medical professionals as to NR's condition, his prognosis, and the burdens and benefits of continuing treatment. I can summarise that consensus without having to set out the evidence each witness has given:
- i) Brain malformation – NR has severe brain abnormalities which may all form part of a neurogenetic disorder. They include callosal agenesis (partial or

complete absence of the connecting fibres between the two hemispheres), bilateral cortical dysgyria (dysmorphia of the gyrus within the cortex), and dyplastic basal ganglia (abnormal cells within the basal ganglia). Brain abnormalities were recognised on ante-natal scans. Due to these abnormalities NR has severe cognitive and motor impairment – he is incapable of speech or purposeful movement – and he suffers epilepsy. His pituitary gland is underdeveloped.

- ii) Epilepsy – I was told in oral evidence that NR has almost constant abnormal electrical activity which is presumed not to cause him distress or pain, but with more occasional seizures with motor manifestation, which is presumed to cause him distress but which are currently relatively well controlled with medication, albeit he is at risk of further seizures at any time.
- iii) NR was born with a cleft lip and palate, which have not been corrected surgically, and bilateral anophthalmia – he has no eyeballs. He has been given a prosthesis in one eye. He has no Eustachian tubes making him susceptible to ear problems.
- iv) NR has a gastrostomy and jejunostomy but is currently fed by total parenteral nutrition (“TPN”) through a PICC – a line inserted into his right arm which delivers nutrition and hydration to a central vein. He has previously had central lines sited elsewhere and I was advised that if this line fails it will be very difficult to find another point of entry to deliver TPN. Enteral feeding via gastrostomy has caused distress to NR.
- v) NR was discharged home for care at about six months of age. He had periods of in-patient care for various complications until March 2023 when he was admitted for the last time. He has been an in-patient at King’s College Hospital Paediatric Critical Care Unit since then. He had some periods of invasive intubation in March to July 2023. He suffered ear infections in 2023 and developed mastoiditis requiring surgical drainage in July 2023. Sadly the infection spread to his brain, causing ventriculitis for which he required a six week course of antibiotics. This caused extensive thinning of the skull bones. Recently, discharge from the ears was again noted. It is currently being investigated whether this is a cerebro-spinal fluid leak or infection.
- vi) In October 2023, NR suffered two cardiac arrests and required emergency intubation. He has remained on invasive intubation ever since, a period now of six months. He has an endotracheal tube in situ. His ventilator settings have varied over time. Recently it has been possible to reduce the respiratory rate to 25 from 30. At times he has required very high ventilator pressures with high oxygen saturations but those are currently lower than they have been at their highest. Nevertheless, it is likely that significant damage has been caused to his lungs and his ability to breathe independently will have been significantly compromised. He requires frequent suctioning for excessive secretions. He has low volume lungs on x-ray. The consensus medical evidence is that he will not be able to breathe for himself if extubated and that non-invasive ventilation would not be viable for a prolonged period.
- vii) NR has suffered a number of episodes of severe sepsis with septic shock. In January 2024, his central line had to be changed when it became infected and he developed septic shock. In February 2024, he suffered septic shock again and positive blood cultures for staphylococcus epidermidis were returned from peripheral blood cultures and his PICC line. Unfortunately, this followed a period when ventilator pressures had come down and discussions had been

held about the possibility of a trial of extubation. His sepsis prevented any such planned trial. NR has had multiple courses of antibiotics.

- viii) Osteopenia – NR has osteopenia causing a reduction in bone density. Recently his father noted that he was in discomfort in one leg on being moved and x-rays confirmed a hairline fracture of the distal femur. I was shown a photograph of the Robert Jones splint applied to NR’s leg. Mr R had taken the photograph on his mobile phone. The bandaging appeared to be around NR’s lower leg and only loosely around his knee. This led to some questioning about whether the splint had slipped. Dr C was recalled to give evidence and appeared to accept that the splint had slipped and that it had been re-applied during the hearing and was tighter in order to give better support. The fracture had been caused by normal handling rather than trauma and is due to reduced bone density. This mandates very careful handling to try to prevent further fractures. NR’s osteopenia was recognised last year but the recent femoral fracture will lead to renewed consideration, and discussion with Mr and Mrs R, as to whether treatment with bisphosphonates should be commenced.
9. The trajectory of NR’s health has been one of deterioration. His physiological reserves are increasingly depleted. He has suffered multi-organ damage. Dr Nadel has advised that his life expectancy is now no more than six months although there can be no certainty: he may suffer further sepsis and septic shock at any time and not survive. That prognosis was agreed by Dr C and Dr F. I understand the medical consensus to be that NR would not now be able to be treated with non-invasive ventilation for a prolonged period and that after extubation with a view to palliative care - which, barring any episode of severe sepsis or other acute problem, could feasibly be done at his home - NR would survive only for a few hours or at most a few days.
10. The parties had no questions for the Guardian. Her reports are of great value to the court. She has visited NR in hospital a number of times and has spoken at length to the parents. She informs the court of how NR was a much wanted child, Mr and Mrs R having tried to conceive for a long time. He is their only child. They knew from the second ante-natal scans that he had congenital abnormalities. After further scanning they were told that he had no eyes, that he had brain malformation, and that he would be unlikely to be able to move for himself when born. Due to the expert care NR received after his birth, and the dedication of his parents, he was able to be transferred home into their care, supported by professionals, at the age of about six months. He could be taken outside for activities and even went to a pool. He attended a special nursery. He had a special chair to enable him to sit. He had a level of awareness of the world around him, as the Guardian reports:
- “NR’s mother has told me that he did have a level of awareness when he was at home and that he would respond to sounds and touch which was evident when he was taken outdoors to the park, in the swimming pool and at nursery. I have seen a video and photos that NR’s mother has on her phone, which appear to show NR responding positively when being held by his father, chuckling and smiling.”
11. Sadly, since his admission in March 2023 NR has deteriorated. In particular, he has had episodes of sepsis, cardiac arrests, and has required invasive ventilation for six

months. On the other hand, having come through some very stormy events he is currently relatively stable on ventilation. One focus of questioning of professional witnesses at court was on NR's current experience of pain and pleasure. NR is currently able to tolerate mechanical ventilation without sedation but, Dr Nadel advises that this "suggests very impaired brain function, with limited responses to either painful or pleasurable experiences." He has exhibited signs of distress and pain such as grimacing, crying, and raised heart rate. He has been on long courses of pain relief previously, for example when he had pancreatitis. Currently he still has occasional pain relief, including after diagnosis of his recent femoral fracture, but is not on constant analgesia. In addition to sources of pain, NR has to suffer the discomfort of constant interventions needed to keep him alive and stable. Dr C told me that on one day during the hearing, NR underwent suctioning on eleven occasions. Dr Nadel has advised that "it is clear that the interventions that he requires to keep him relatively stable are distressing and cause him discomfort. These include endotracheal suction, urinary catheterisation, moving him ... and infusions to prevent pressure sores." All the witness evidence, including that of the parents, is that NR suffers discomfort at best, pain at worst, and distress, albeit it appears that his capacity to experience pain is now more limited than previously, probably because of his reduced cognitive functioning.

12. Mrs R has said in her statement of 18 March 2024, "We absolutely know – because we see and feel it – that he knows us and knows he is loved." Prior to hearing oral evidence there was virtually no evidence other than from Mr and Mrs R, that NR had awareness of what might be called beneficial or positive interactions with the world around him, as opposed to experience of pain and distress. Matron E stated in her written evidence:

"Nursing staff do not feel that NR has any recognition of familiar people or that there is a differentiation between his response when nursing staff undertake his cares or when his parents undertake these. NR's parents are observed to be appropriately affectionate with NR in a way that supersedes nursing care but without visible response or change in NR's demeanour in response to this."

13. In cross-examination, however, Matron E apologised for the wording of that part of her statement, saying that nursing staff had noted that in response to "doing cares" on NR they found that if touched in a certain way he will stop grimacing and crying, and will return to a calmer state. Similarly, Dr B spoke in his oral evidence to an experience he had not included in his written evidence, namely that after Christmas 2023 he had examined NR and tested for a gag reflex. NR had been distressed by the test but when the distressing stimulus was removed and his hand was touched by his mother, he settled. I understood him to be accepting that NR may have been comforted by his mother's touch. However, he also spoke of an occasion when NR was caused more significant distress by an intervention and could not be consoled.
14. Mr and Mrs R's evidence is that NR is soothed by being held, by touch, and by the sound of their voices. They were taken by surprise by oral evidence from Dr B that NR was deaf. Dr B said that CT scans showed that NR's ossicles (the small bones in the middle ear that transmit vibrations to allow a person to hear) were damaged by

infection to the extent that they could not be seen radiologically. Given that evidence of anatomical destruction, he did not think that NR could hear. He did not rule out that NR might be able to sense sound in some other way - I assume through the conduction of vibrations – but he said that NR’s higher cortical functioning was so impaired that he did not believe that he could process any such experience such that he could be said to be conscious of it. Again, evidence about NR being unable to hear was not in the written evidence and Ms Gollop KC informed the court that the parents had been unaware that clinicians thought that NR could not hear. In response, they provided the court with evidence from a music therapist who had attended NR on his recent birthday. She made contemporaneous notes, and wrote to the parents that:

“I felt that he visibly responded to the session, evidenced through his eye movements, mouth movements and occasional physical movements. While he may also have been responding to vibrations, visual cues and to feeling the instruments, my sense was that he was also hearing the music and responding to the sounds. For example I felt that he responded to the sound of my voice.”

15. The Guardian made very careful observations of NR and his parents on visiting the hospital. She wrote in February 2024:

“At one point when NR’s mother put her hand slightly underneath his side, he grimaced and appeared to show some discomfort however this subsided quickly as his mother stroked his hand and spoke to him. Sometime later NR again grimaced and opened his mouth as if to cry however he did not make a sound and his mother was quick to check whether he was showing discomfort because his nappy needed to be changed. Upon checking his nappy, NR had defecated, and his mother set about changing him, gently wiping him clean and putting on a new nappy in a timely and efficient manner. I watched NR as his mother carried out this task and he showed no signs of discomfort.

...

It is not possible to be sure with any certainty whether NR has an awareness of his surroundings. His parents are convinced that NR can hear, and they described how he demonstrated this when at home they would play music and sing to him. When I was at the hospital, I observed NR to respond to his mother touch, when he stopped grimacing when she gently stroked his foot and rubbed his leg, whilst talking to him. This happened on three occasions during the three periods that I was at NR’s bedside with his mother and whilst it provided only a snapshot and may differ from a clinician’s interpretation, it did appear that NR’s mother’s touch and voice resulted in a change to his facial expression and settled him.”

16. Dr Nadel, instructed by the parents, has advised that, “[NR] has no obvious awareness of his surroundings...” The parents did not call Dr Nadel to give oral evidence and he has not responded to any of the further oral evidence or the evidence from the music therapist, that I have received. Furthermore, the therapist’s evidence was not tested in court and Dr B did not have an opportunity to respond to it.
17. I have no evidence that since his admission to the critical care unit a year ago he has shown signs of spontaneous pleasure, or responses to stimulation such as a smile or burbling which might indicate pleasure as opposed to consolation.
18. There is no treatment that can be given to NR that will improve his brain function. His multiple conditions and complications are managed well within the hospital but the goal is to minimise the pain and distress to NR rather than to bring about any improvement in his underlying conditions, because that cannot be achieved. Dr A described it as “heartbreaking” to see NR deteriorating and to know that interventions will not be able to improve his life and that it is impossible to give him a life without pain.
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.
20. Dr Nadel, instructed by the parents, concludes that the burdens of treatment outweigh its benefits to NR. In his opinion NR suffers a “high burden of illness despite attempts to mitigate the burdens of his condition” and the invasive ventilation, parenteral nutrition, and other interventions impose “significant burdens” on him. He states that “NR is unlikely to derive any benefit from continued life sustaining treatment in the absence of any discernible evidence of clinical improvement.” He concludes that “it would not be in NR’s best interests for life sustaining treatments to continue to be provided.” Dr F, who has provided an independent second opinion to the Trust, and who gave evidence to the court, concurs that “invasive ventilation may defer his death – although this is not guaranteed – but it will inflict harm, without relieving the underlying burdens of his disease.” The treating clinicians and Matron E are of the view that it is in NR’s best interests now to withdraw life sustaining treatment because, as Dr A put it to the court, the burdens “far, far outweigh” any benefits.
21. Mr and Mrs R gave evidence together. They were composed, articulate, and showed a quiet determination to make their case. Their evidence was powerful. They told me that it had never entered their minds to terminate Mrs R’s pregnancy after they had

been told of NR's congenital abnormalities following scanning. They thought then, and think now, that NR is a gift from God. He has enhanced their lives. His life is meaningful and has given meaning to the lives of others, including them. They know that as parents of a severely disabled child they cannot give him the range of experiences that they could give a child without his disabilities, but they can give him unconditional love and the knowledge that they are always there for him. They regard it as wholly unethical to bring about his death by choice.

Legal Principles

22. Most decisions about withdrawing life sustaining treatment from a child are made by agreement between clinicians and parents, not by judges. Here, despite dialogue, good relations, and mutual respect, there is no agreement between the Trust and the parents and so, upon the Trust's application, the court is required to make decisions about NR's treatment.
23. In making those decisions, a judge puts aside their own ethical views or any religious beliefs and applies the key, well-established, legal principles. 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.”

24. 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 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.

25. These principles apply equally to any child whatever their extent of disability or illness, but the court has to scrutinise the particular facts of each case. A judgement as to the best interests of a child will require consideration of their specific condition and prognosis, their circumstances, and the benefits and burdens of continued treatment. Application of the principles to the specific child 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 v A and others* [2022] EWHC 2422 (Fam), the court recognises and respects the child's innate human dignity by focusing on the child's particular circumstances and conscientiously applying the established legal principles, not by making a decision based solely on the judge'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.
26. NR's own experience of pain and pleasure is a highly relevant consideration but, as Baker LJ observed in *Parfitt v (1) Guy's and St Thomas' Children's NHS FT (2) Knight* [2021] EWCA Civ 362 at [60], harm can be caused to a person even if they are not conscious of it:

"The proposition that no physical harm can be caused to a person with no conscious awareness seems to me to be plainly wrong. As I observed during the hearing, the law clearly recognises that physical harm can be caused to an unconscious person. In the criminal law, for example, an unconscious person can suffer actual or grievous bodily harm and it would be no defence to a charge under the Offences against the Person Act 1861 that the victim was unconscious. The judge was in my view entirely justified in citing examples from the law of tort in which it has been recognised that physical harm can be caused to an insensate person. As Mr Mylonas observed, if the proposition advanced on behalf of the appellant was correct, there would be no limit on a doctor's ability to perform any surgery upon any insensate patient. For my part, I fully endorse the judge's reasoning for rejecting the appellant's proposition at paragraph 76 of his judgment."

27. Parental wishes are relevant to a decision about the withdrawal of life sustaining treatment. In *Gard and Others v the United Kingdom* - 39793/17 (Decision [2017])

ECHR 605 (27 June 2017) the ECtHR identified the requirements that the state has to meet to satisfy its positive obligations under Art 2 of the European Convention on Human Rights in a case where life sustaining treatment may be withdrawn:

"[80] In addressing the question of the administering or withdrawal of medical treatment ... the Court has taken into account the following elements:

- the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2;
- whether account had been taken of the applicant's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel;
- the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests."

In any event, the parents have Article 8 rights and their wishes have to be taken into account in that context. Nevertheless, parental views and wishes do not take precedence – the child's best interests prevail. In *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ observed:

"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

28. Regard must also be had to the Art 9 Convention rights of the parents to freedom of thought, conscience, and religion (*Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) per MacDonald J at [116]). The Court of Appeal addressed the relevance of religion and culture to the assessment of a child's best interests in *Fixsler v (1) Manchester University NHS Foundation Trust* [2021] EWCA Civ 1062. Baker LJ stated at [81]:

"The family's religion and culture are fundamental aspects of this child's background. The fact that she has been born into a devout religious family in which children are brought up to follow the tenets of their faith is plainly a highly relevant characteristic of hers. Under s.1(3)(d), the court is required to have regard to the fact that Alta is from a devout Hasidic family which has very clear beliefs and practices by which they lead their lives and that, if she had sufficient understanding, she too would very probably choose to follow the tenets of the family religion. I agree with Mr Simblet that this is a central part of her identity – of "who she is". It is unquestionably an important factor to be taken into consideration. But it does not carry pre-eminent weight. It must be balanced against all the other relevant factors."

29. It cannot be assumed that NR would have developed the same or similar religious views as his parents. NR himself has never had the opportunity, due to his age and

disabilities, to form any ethical or religious views or affiliations. Nevertheless, I should take into account the parents' particular convictions and that NR has been born into a family that hold to those convictions.

Professional Guidance

30. 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:

"The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit:

I. When life is limited in quantity

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- A. Brain stem death, as determined by agreed professional criteria appropriately applied
- B. Imminent death, where physiological deterioration is occurring irrespective of treatment
- C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

II. When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
- C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

III. Informed competent refusal of treatment"

Analysis and Conclusions

31. In her Introduction to the RCPCH's framework for practice, the then President of the College, Dr Hilary Cass, said:

"In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child? There is no technology

to help us here—only guidance, discussion, and adequate time and information for truly shared decision making.”

Decisions about whether to continue life sustaining treatment are very difficult to make. It helps to bear in mind Baroness Hale’s judgment in *Aintree* (above) where she said that the focus is on whether to give a particular form of treatment, rather than on whether to withdraw or withhold it. The key question in the present case is whether it is in NR’s best interests to continue invasive ventilation and other life sustaining treatments. The parents have told me that they cannot see the difference between withdrawing invasive ventilation and euthanasia. I understand their viewpoint that there is no ethical difference between deliberately ending NR’s life and changing care from invasive ventilation to palliation. The likely end result of each would be NR’s imminent death. However, the law draws a clear line between killing another and withdrawing treatment.

32. Mr and Mrs R have spoken powerfully about the feeling that they have lost control. I accept that they have. It is generally expected that, in the exercise of parental responsibility, parents of young children will make decisions about medical treatment on their behalf. However, where clinicians consider that the decisions being made by parents about a child’s treatment are not in the best interests of the child patient, the law allows for an application to be brought to court for a determination, including determination of whether it would be lawful and in a child’s best interests to discontinue life-sustaining treatment. A judge, not the parents, then makes a decision on that application. It is not open to the judge simply to defer to parental wishes – the law requires the judge to take those wishes into account but to make a determination as to what is in the child’s best interests. Therefore the parents do lose control over a fundamental decision involving their child. Accordingly, it is important that everything is done to try to build a consensus between clinicians and parents so that parents do not feel that they have been stripped of their role and their responsibility for their child, and to avoid if possible the need to make a court application. The RCPCH framework for practice states,

“Decisions to limit treatments - or what treatments should be given - should be made by clinical teams in partnership with, and with the agreement of, the parents and child (if appropriate). They should be based on shared knowledge and mutual respect. Where possible they should be made in advance of acute events in the form of care plans and be available for all relevant parties.”

In this case clinicians sought advice about NR’s case from the clinical ethics forum within the Trust in 2023 but without participation of the parents. Ms Gollop KC took the Trust to task for this omission and has referred me to the judgment of Russell J in *Great Ormond Street Hospital for Children NHS Foundation Trust v MX and Ors* [2020] EWHC 1958 at [21] to [23] where she criticised the exclusion of parents from ethics committee meetings. But I note that the RCPCH’s practice framework makes a distinction between clinical ethics committees, which form part of an ethics support service and clinical ethics forums which are designed to be part of clinical training and education. In relation to ethics committees, the guidance states:

“The function of an ethics support service in individual case reviews is to analyse the ethical dilemma(s) involved in order to help parties understand the relevant facts and differing values and to try to achieve better understanding between the parties involved. They may also have important mediation and conciliatory functions and may serve to protect patients’ rights. Outcomes of such discussions should form part of the child’s clinical record.”

Whereas, in relation to ethics forums, the guidance states:

“Ongoing delivery of training and the facility to reflect on challenging issues are key elements of good clinical practice. It is essential that the psychological and spiritual dimensions of care continue to be fully considered. Hospitals may also consider having an educational clinical ethics forum that periodically meets to review difficult cases or establish other mechanisms for this purpose.”

Perhaps the distinct functions of what are intended to be two different bodies were not clearly delineated in this case where the clinicians took a specific case to the clinical ethics forum for discussion. The forum therefore acted in the role of an ethics committee. I note that the advice from the forum was communicated to the parents and that Mr and Mrs R have been involved in multi-disciplinary team discussions. Nevertheless, they felt excluded and that a fundamental decision about the direction of NR’s care and treatment was taken without them. In court, Dr C undertook to take the issue of parental involvement in ethics discussions back to the Trust and to his professional association. It is not for me to direct how Trusts should organise ethics committees and forums, but the RCPCH guidance does stress the importance of involving families in decision-making about life-sustaining treatment and palliative care. Dr F said that his Trust now involves parents in all ethics committee discussions about such decision-making and that it has many advantages with no disadvantages. Any information given at such meetings should already have been shared with the family in any event.

33. The parents cannot accept that a choice should be made that would end NR’s life prematurely. However, the fact is that there is a choice that has to be made every day of NR’s life. They themselves told me that they reflect, daily, on whether they are doing the right thing for NR. It is a choice to intervene just as much as it is a choice not to intervene. Someone has to make that choice and, when clinicians disagree with parental choice to a sufficient extent, they can ask the court to make the choice according to the law.
34. The preservation of life is a very important presumption. It is not lightly displaced. Generally, it would be unlikely to be displaced only because the burdens of treatment modestly outweigh the benefits. The presumption that life should be preserved respects the innate dignity of all human life, as does the intense focus on the best interests of the individual concerned.

35. Miss Gollop KC invited the court to consider whether, thus far, the courts have too easily allowed the presumption that life should be preserved to be displaced. Allied to that submission, she warned against presuming what are the experiences of a severely disabled child such as NR. He cannot speak for himself but if he could, might he say something different from what the clinicians suppose? Might he not align himself with his parents in wishing to preserve the loving bond within this family for as long as possible, even with the burdens of living with his severe conditions and the interventions required to keep him alive?
36. I do heed the warning that the court cannot be certain what NR experiences but the need to avoid speculation cuts both ways. In the absence of supportive evidence, I cannot assume a higher level of consciousness and experience. The court must be guided by the evidence and cannot base its determinations on speculation.
37. NR cannot see. He was born without eyeballs. He has eye lids and can blink. He has a prosthetic eyeball in one eye. Radiological evidence shows that he does not have ossicles in his middle ear that could function to allow him to hear. Any capacity to be soothed is very likely to be through touch rather than sight or hearing although there is a possibility that somehow NR can sense sound through vibrations. He has very thin skull bones following his serious infection in 2023. Perhaps that and his unusual brain allows him to sense sound differently from someone without those abnormalities. Weighing all the evidence I conclude on the balance of probabilities that NR is able to respond to external stimuli, not only painful or distressing stimuli, but also some stimuli designed to comfort him or stimulate him in a positive way. However, this capacity to respond to positive stimuli is extremely limited. He cannot generate pleasure himself – there is no evidence of any signs of spontaneous pleasure. Many of his responses will be reflex responses. Dr Nadel considers that NR “has no obvious awareness of his surroundings and while he may derive some comfort from touch/cuddling or voice of his parents, it does not appear to be meaningful.” The parents object to any suggestion that such interactions are not meaningful. I understand Dr Nadel to be saying that NR himself cannot understand or appreciate soothing touch or sound in any conscious way. He can respond but not process what he is responding to. It is difficult to term this response as “pleasure”. Reactions to painful stimuli can be reflexive rather than conscious, and NR’s response to soothing touch, and maybe even to sound, is likely to be similarly reflexive rather than a conscious experience. It is not possible to know what NR’s experiences are with any certainty but on the balance of probabilities I conclude that whilst NR can respond to painful and pleasurable stimuli, his awareness of such stimuli and the world around him is extremely limited.
38. On reviewing the evidence, I found Dr F to be a very fair, thoughtful, and experienced witness. His analysis was very clear – there was no benefit to NR from continuing invasive ventilation and it was in his best interests for him to be extubated “as soon as possible”. He recognised that extubation would be likely to lead to NR’s death within hours, although he could possibly live for a few days – it is very difficult to predict exactly how a child who has adapted to low oxygen levels and invasive ventilation over several months will respond to extubation. He could not see any possibility of NR being kept alive with non-invasive ventilation at home.

39. Dr C broadly agreed with Dr F's evidence. Dr Nadel did so too although he entered some caveats in some parts of his written evidence. He has advised that:

“In my opinion it is not in NR's best interests to continue provision of life-sustaining treatments if it is clear that he is not able to wean from the ventilator to the point of extubation; and/or if it is clear that he is not able to be fed enterally; and/or if he has intractable and uncontrollable seizures.”

The evidence persuades me that there is 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” is possible but there is no realistic prospect of NR transferring to non-invasive ventilation for a prolonged period. The evidence also establishes that there is virtually no prospect of NR moving to fully enteral feeding. He might be able to tolerate some limited enteral hydration or even feeding but he will continue to be dependent on parenteral nutrition. When he is enterally fed he appears to suffer from abdominal pain and distress. Therefore the conditions for weaning NR from the ventilator to the point of extubation (other than one-way extubation) do not and will not arise.

40. The consensus amongst the medical professionals, including Dr Nadel as the expert witness relied upon by the parents, is that if NR remains on invasive ventilation and receives other life sustaining care and treatment his life expectancy is at most 6 months. I accept the uncertainty around such a prognosis but proceed on the basis that it is unlikely NR will survive longer than that period. What is quite clear is that there is no prospect at all that continued life-sustaining treatment will bring about an improvement in NR's underlying condition. Most of his care and treatment is focused on sustaining life and mitigating his discomfort. Prolonged invasive ventilation has caused damage to NR's lungs and reduced respiratory function. Accordingly, it causes him harm, albeit it keeps him alive. Generally, NR's condition has deteriorated over the past six months and his physiological reserves have become increasingly depleted. Life-sustaining treatment is futile in the sense that it will not bring about any improvement in NR's condition, indeed NR will be likely to continue on a trajectory of general deterioration. Life-sustaining treatment will however keep NR alive at least for a limited period.
41. There is unanimity amongst the medical professionals who have given evidence, and Matron E, that the burdens of NR's conditions and treatment outweigh the benefits to him from life-sustaining treatment. Dr Nadel writes of the “high burden of illness” and medical treatments imposing “significant burdens on NR, both pain and discomfort as well as the need for invasive devices and frequent blood tests.” With respect to Mr and Mrs R, I consider that they have understated the extent of the burdens on NR caused by his condition and his treatment. They referred to him being “slightly” different from other children, and that any four-year-old child would be expected to sometimes cry or suffer some discomfort or distress. It cannot be known for certain what NR's subjective experience is like, but he has an endotracheal tube permanently in place, requires frequent suctioning, and undergoes other invasive procedures such as blood tests. He has suffered a femoral fracture. If, as the parents firmly maintain, he has awareness, then sadly that would mean that he has some awareness of these interventions. If his awareness is, as I have found, very limited, he

nevertheless suffers a significant amount of discomfort, pain and distress from his conditions.

42. Dr D, Paediatric Palliative Medicine Consultant, has advised the court that a redirection of care is appropriate for NR and is in his best interests. Transfer home, or to a hospice, for extubation would be possible. She gives details of the arrangements that might be made. However, whilst NR is currently relatively stable, if his “clinical condition becomes more unstable, and symptoms more challenging to manage, it may be that hospital or hospice would be the preferred location for end of life care, to avoid NR or his parents from any added distress at home.” Hence, every day is significant for NR both because he suffers significant burdens from his condition and treatment, and because the opportunity for his life to end at home in the care of his parents may be lost at any time.
43. When considering the wider benefits and burdens to NR I am struck by the evidence of the Guardian as to NR’s time with his parents at home. He has always been severely disabled, unable to walk or talk, and has a great deal of treatment and constant care. However, with considerable support and with intermittent periods of in-patient care, he was able to live at home with his parents from the age of about 6 months until his admission in March 2023. During that period he would be taken out to the park in a pushchair, he had a number of sessions at a special needs nursery. He had time in a swimming pool. There is clear evidence that he derived pleasure from activities and contact with his parents – the Guardian has seen a film of him smiling and chuckling when cuddled by his father. He accompanied his parents to church. His Godfather is a priest who has given unswerving support to the family. Mr and Mrs R are part of a close community through their church and NR was able to be introduced to that community. Now, he is attached to a mechanical ventilator, he is on total parental nutrition, he requires frequent suctioning and many other daily interventions. Recently it was possible to transfer him to the Hospital Chapel on a mobile ventilator but that is a rare event and one which takes a great deal of planning and management. He will never be able to live outside the critical care unit, he will never live at home, and there is no hope for any progress in his underlying conditions. He is confined to a bed on a busy unit. He no longer shows signs of pleasure other than being consoled when distressed. His awareness of his environment is minimal. There has been a marked change for the worse in his condition and in the balance of burdens and benefits to NR over the past year or so and his life has become ever more diminished.
44. NR continues to benefit from the unconditional love and support of his parents. Their devotion to him is deeply moving. The extent of his awareness of their presence and his interactions with them cannot be known with any certainty, but I accept their evidence that he can be comforted by them. Their dedication to him is unquestioned and many of the clinical professionals have spoken with admiration of the parents’ devotion and of the skilled care they give to their son. Mr and Mrs R spoke powerfully to the court about how NR’s life has meaning. Mrs R considers the withdrawal of life sustaining treatment to be euthanasia. They feel that it would be discrimination on the grounds of disability to grant the Trust’s application. Mrs R asked me why NR should be “forced to die”?
45. These heartfelt and reasonable challenges deserve answers. Firstly, the court must apply the law as it is. I understand the ethical issues surrounding dilemmas of

“killing” and “letting die”, but in law a declaration that a particular treatment would be contrary to a child’s best interests, and therefore unlawful, concerns the continuation of that treatment, not a direction to end a life. It does not permit an act of euthanasia. Secondly, hard though it is for all involved, but by far and away mostly for the parents, the decision for the court is not whether continued treatment allows parents to continue to provide loving support to their child, it is solely whether it is in the best interests of NR. Thirdly, the law applies equally to all children, whatever the extent of their disability or illness, but in considering a child’s best interests the court must have regard to their particular circumstances. That is not discriminatory. Fourthly, when so much medical intervention is required to keep a child alive, there may come a point at which the burdens of that treatment outweigh its benefits to the child to such an extent that the child should be spared the treatment and those burdens even though their life will probably end sooner than if the treatments were continued. They are not “forced to die” but should not be “forced to live” and may be relieved of the burdens of treatment and be “allowed to die”.

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. He is confined and no longer shows pleasure, only some comfort when distressed.
47. NR has had periods of stability and then periods of marked deterioration, for example when he suffered cardiac arrests in October 2023. There is an opportunity now for him to go home, albeit for extubation at home, with death likely to follow soon thereafter. That opportunity could be lost at any moment if he suffers a further sudden deterioration. Mr and Mrs R told me that if NR is to be extubated, they would prefer that to happen with palliative care support at their home.
48. The view of those treating NR and of the medical professionals who have given evidence before me, is that the burdens of continued life sustaining treatment outweigh the benefits by a sufficiently significant margin that it is contrary to NR’s best interests to continue that treatment. I take the views of the treating team into account. I give due weight also to the parents’ views, which I know are supported by NR’s Godfather, their priest. I take into account their wishes. I am mindful of their and NR’s Convention rights. NR’s case clearly falls within IC and IIA-C of the RCPCH’s framework as set out above. The presumption of the preservation of life is strong but, in my judgement, it is clearly displaced in this case.
49. NR’s life has meaning. He has brought joy to his parents and others. He has brought out the virtues of his parents: love, kindness, patience, and devoted care. He has been

cared for by dedicated professionals who have come to know him well. He has been known by his parents' church community and supported by his Godfather. He has made his mark on the world. I understand his parents' concern that clinicians and others cannot see, let alone experience, the bond between NR and them. But his parents' love and devotion to him is so strong that they cannot bring themselves to accept what those less personally connected to NR can see, namely that the burdens to him of treating him to keep him alive far outweigh the benefits and that it is in his best interests for life-sustaining treatment to cease.

50. Accordingly, and with great sadness, I conclude that the Trust's application should be granted and I shall declare that it would be lawful and in NR's best interests for invasive ventilation and other life-sustaining treatment to be discontinued. Given NR's current relative stability, it would not be contrary to his best interests, and it would be in accordance with his and his parents' Article 8 rights, for urgent preparations to be made with a plan for him to be transferred home, if that is what his parents still wish to happen. This would be for the purpose of extubating him at home with a plan not to re-intubate but to provide palliative support only. There may be a limited opportunity for this to happen and so there is some urgency, but a number of clinicians, including the palliative care team, need to be involved, available, and ready. I hope that a plan can be agreed and incorporated in a draft order for me to consider when this judgment is formally handed down. An alternative plan for transfer to a hospice, or extubation in hospital will also be required in the event that transfer home becomes impossible due to a change in NR's condition. In the meantime, the previous order as to ceilings of treatment will continue to apply.
51. Mr and Mrs R's dignified manner, devotion to their son, and strong faith have made a deep impression on all those involved in NR's care, and on the court. The decision I have made is contrary to their profound beliefs and wishes but I hope that at some point they can find some peace knowing that they have done everything they could have done to support, love, and cherish their son.