Neutral Citation Number: [2026] EWHC 452 (Fam)

Case No: FD25P00762

**IN THE HIGH COURT OF JUSTICE**
**FAMILY DIVISION**
**SITTING AT MANCHESTER CJC**

Date: 27 February 2026

**Before**:

**MRS JUSTICE THEIS DBE**

\- - - - - - - - - - - - - - - - - - - -

**Between:**

**Manchester University NHS Foundation Trust** **Applicant**

**- and -**

**(1) RNM**
**(2) RNF** **Respondents**
**(3) RN (by his Children's Guardian)**

\- - - - - - - - - - - - - - - - - - - -

**Sam Karim KC and Helen Gardiner** (instructed by **Weightmans LLP**) for the **Applicant**
**Joseph O'Brien KC and Kate Spence** (instructed by **Irwin Mitchell LLP**) for the **First and Second Respondents**
**Lorraine Cavanagh KC** (instructed by **Cafcass Legal)** for the **Third Respondent**

Hearing dates: 23 – 26 February 2026
Judgment date: 27 February 2026

\- - - - - - - - - - - - - - - - - - - -

# Approved Judgment

.............................

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published. Nobody may be identified by name or location. There is a **Transparency Order dated 27 February 2026.** The anonymity of everyone other than the lawyers or anyone identified in this 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.

**Mrs Justice Theis DBE:**

## Introduction

1. The court is concerned with RN age 3 years. He is the mother and father's youngest child. He was born very prematurely, at 23 weeks, and has spent all his life in hospital. This application is brought by the Manchester University NHS Foundation Trust (The Trust) under the inherent jurisdiction. They seek orders that would permit them to withdraw ventilatory support and to approve the palliative care plan they propose.

2. RN's parents oppose that application. It is not in issue in this case that his parents have provided devoted and loving care to RN. They have attended his hospital bedside each day (often more than once a day) for over three years. They work in close partnership with RN's clinical team and provide much additional support for RN's day to day needs.

3. RN is a separate party to these proceedings. He is represented through his Children's Guardian, who supports the application by the Trust.

4. These proceedings were issued in November 2025. The court has closely case managed this application to avoid delay. There has been the opportunity for the parents to secure expert opinion from the relevant medical specialists.

5. I have heard oral evidence from:
   (1) Members of the clinical team: Nurse D, Clinical Ward Manager, Dr E, Consultant in Paediatric Respiratory Medicine (who the Trust sought a second opinion from prior to the issue of proceedings), Dr Z, clinical Consultant in Paediatric Respiratory Medicine, Dr C, clinical Consultant Paediatric Intensivist, Dr B clinical Consultant Paediatric Neurologist
   (2) Each of the experts instructed: Dr Brierley, Consultant Paediatric Intensivist, Dr Taylor, Consultant Paediatric Neurologist and Dr Rosenthal, Consultant Respiratory Paediatrician.
   (3) Both parents'.
   (4) Children's Guardian.

6. One of the issues that has concerned the court is the question of delay in issuing proceedings. Whilst recognising the importance of collaboration and working with parents, or those with parental responsibility, in these difficult cases (as set out in the Royal College of Paediatric and Child Health Guidance '*Making decisions to limit treatment in life-limiting and life-threatening conditions in children'* (RCPCH Guidance)), if agreement cannot be reached consideration should be given to devising a structure to avoid delay in bringing the matter before the court. In this case there was reference in the papers to the matter being referred to the court in June 2024 and January 2025. The Trust's solicitors wrote to the parents solicitors in April 2025 stating an intention to issue proceedings, which were not issued until November 2025. That delay is accepted by the Trust and they recognise the distress that caused to the family, for which the Trust apologises.

7. In the position statement filed by the Trust at submissions they state they are actively considering a resolution framework/protocol for similar cases, which would include, upon identification of a disagreement:
    (a) The possibility of obtaining a second opinion within a specified period.
    (b) A best interests meeting involving clinicians and family members (plans proposed by the clinicians would be circulated prior to any meeting).
    (c) In the event of
        (i) a continued disagreement, or
        (ii) a difference of medical opinion, an expectation is that an application would be brought.
    (d) The resolution framework/protocol would recognise
        (i) that steps should be taken to resolve the relevant issues without the need for proceedings (as outlined in the RCPCH Guidance),
        (ii) but that delay may have an effect on the child's welfare and where resolution cannot be achieved, then proceedings should be issued, and
        (iii) the importance of communication with the family throughout.

8. Such a development would be welcome, and help avoid the delays that happened in this case.

## Background

9. Following his birth at 23 weeks he spent the first 5 months in the Neonatal Intensive Care Until (NICU). He needed to be intubated after 12 minutes and then had invasive ventilation with an endotracheal tube for nearly 3 months. This was followed by non-invasive ventilation for about 6 weeks and 11 days on heated, humidified high flow oxygen. He had six failed extubations.

10. An MRI in April 2023 showed permanent and severe widespread damage to different parts of his brain and spinal cord. His diagnosis includes chronic lung disease, left vocal cord palsy, hypothyroidism, gastro-oesophageal reflux disease, hearing loss and no cough or gag reflex.

11. At the age of about 3 months he developed seizure like episodes.

12. RN was transferred to the High Dependency Unit (HDU) in June 2023 on non-invasive ventilation, via a mask on a portable ventilator with small trial times off, which were unsuccessful. He required frequent admissions back to Paediatric Intensive Care Unit (PICU) due to poor respiratory function. Whilst on HDU training was given to his parents enabling them to assist with RN's care including by way or oral suction, nasal suction, repositioning and bathing. He remained on HDU until July 2024 when he was transferred to the PICU due to RN's inability to maintain his own airway via a non-invasive mask and requiring intubation via an Endotracheal Tube (ETT) with increased respiratory support via a ventilator. As a result, RN had to be transferred to PICU for 1:1 nursing care and continuous monitoring 24 hours a day from a registered nurse.

## Day to day care for RN

13. His care involves what Nurse D, Clinical Ward Manager, described as the ABCDE approach (airways, breathing, circulation, disability and exposure). Nursing care is required to ensure his airway remains clear by making sure the ETT is properly maintained and secure. This involves daily replacing of tapes securing the tube to his face, checking there are no blockages in the ETT.  The ETT has had to be replaced many times. For that to happen RN requires sedation to stop him moving spontaneously and allow the instrument and tube to be passed into his airway without coughing or pain. This has caused him to have slow heart rates, low saturations and there has been difficulty inserting the tube due to difficult views of his complex airway. He requires regular mouth care to prevent ventilator associated pneumonia and provide adequate oral hygiene. This is supported by the parents, which I have seen in the videos they have sent to the court.

14. For his breathing he requires hourly ventilator observations to ensure the pressure is delivered as planned, breaths are the correct rate and volume of each breath is monitored. RN requires frequent suction every day and throughout the night, even when asleep. This is done using a catheter up his nose, a yanker tube into his mouth or a sized catheter down the ETT. This latter procedure requires members of the medical team, the parents help with the other procedures. RN has constant oral and nasal secretions that he cannot control, he lies on an absorbent pad and towel to catch the secretions as it is not possible to suction them all and the need to keep the secretions away from his skin to prevent moisture associated skin damage. When not suctioned effectively this causes RN to desaturate, with alarms bleeping until all the secretions are cleared.

15. Turning to his circulation, RN requires checks on his temperature and blood pressure every four hours. He has hourly observations of heart rate, respiratory rate and a device in his airway to monitor carbon dioxide. Due to difficulties in accessing his veins a PICC line was inserted in September 2024. To manage the risk of infections this has to be checked hourly and documenting it is secure. It requires weekly dressing change, which has risks involved in removing the plaster.

16. As regards disability, RN is checked every two hours to assess pain. When his scores are high he will appear agitated with eyes rolling and increased twitching. Sometimes this requires escalation to the medical team in case this is a seizure. RN is on medication for seizures. His level of consciousness is also assessed hourly and his pupils assessed 2-4 hourly. This involves shining a torch and assessing pupil size and reaction so if there is a change this can be escalated. Alongside this his Glasgow Coma Scores are recorded. This is a more in depth neurological scale of all the observations combined to assess conscious level, pupillary reactions and limb strength. His verbal response cannot be assessed as his ETT tube goes through his vocal cord and he cannot make a noise, cry, babble or laugh. His response to painful stimuli is low in this assessment as he may pull away and object to a sensation or stimuli he does not like but this is not a purposeful response, and he cannot obey commands due to lack of strength and cognitive ability. He has dystonic, stiff, extended movements which are frequently triggered by suction causing him to have his eyes wide open, go very red faced and very stiff. These dystonic events have significantly increased over the last few weeks and include him arching his back and is described as obviously being in distress. They can be triggered by suctioning, touch, temperature, pain and jittery movements when agitated or unsettled. There is a

carefully titrated plan of medication to try and control these movements, including increasing the baseline medication, with the need recently to increase his sedation medication to manage RN's dystonic episodes, following consultation with the on call neurologist.

17. From a nursing perspective caring for RN requires having to rely on clinical observations and the level of dystonia to ascertain whether he is showing signs of distress, such as going red or jittery. He does not show enjoyment with facial expressions such as fixing and following, smiling and laughing when interacting with others although his parents report some recognition and response to them. RN appears calmer when his IT tablet is on and gets comfort from gentle interactions like hand holding and sensory lights or music.

18. Turning to exposure, his skin is assessed hourly and he is changed position every 2 – 4 hours. Due to the devices, tape changes, excessive secretions pooling, being warm and with moisture in his creases constant monitoring is required. Eye care is required every four hours as they get red and dry or watery. His air filled mattress helps support his pressure areas with regular re-positioning which can often dislodge his feed tube that then needs re-positioning and an RN-ray to confirm the position. He has a P pod chair to enable him to spend some time out of bed making sure all devices are not disturbed and suctioning continues. Apart from these periods in a P pod and cuddles with his parents he remains in his bed.

19. As regards feeding he cannot have anything orally so all his nutrition is via his Naso jejunal (NJ) tube. He has 4 hourly checks to ensure the NJ tube remains in position and the tube is changed every 3 months or when dislodged. RN's medication is also administered via the NJ tube.

## Medical evidence

### Neurological

20. The clinical paediatric neurologist, Dr B, first saw RN in April 2023 when her advice was sought regarding management of his seizures and episodic twitching of his chin. She saw him again in July 2023 and met with the family to discuss the results of his MR scan and EEGs. She discussed the scans with them summarising that they showed the following: a poorly formed brain with excess CSF fluid; brain scarring from intraventricular haemorrhages; hypoxic ischaemic encephalopathy; periventricular haemorrhagic infarction; a very poorly developed brain stem due to extreme prematurity and an MR scan showing significant brain injury. She confirmed her view that whilst time will tell the extent of his neurological impairment there was no prospect of recovery as the brain cells can never regenerate and replace lost cells.

21. A further MRI scan was undertaken in August 2024. It confirmed the previous findings and showed further atrophy and the fluid filled space was more prominent. Dr B is clear that this is due to more cell loss from the first scan to the second and his deterioration is so severe that it is incompatible with life in the long term. As she observed RN's *'presentation is so severe that it is incompatible with life in the long term. While [RN] can be kept alive with invasive support, there would still be an inexorable decline in his condition.'* Dr B discussed the scan with RN's parents,

confirming that the position was unlikely to change and the brain stem is so injured it cannot sustain regular effective ventilation without additional support.

22. Dr B was next involved with RN in January 2025, when her advice was sought regarding antiseizure medication and again in June and September 2025. In her statement she confirmed her opinion that RN's neurological state will not improve, she did not consider RN derives pleasure from life stating *'His best state of 'comfort or being settled' is the one in which he is having least intrusive interventions to sustain life…There is evidence that this is…also decreasing with time and he sometimes needs sedation medicine to keep him settled'.'.* In her analysis she concludes there is no evidence of visual fixing and following which indicates a failure of normal higher-level development in response to visual stimuli. Whilst RN has intact ear structures he lacks the integrity of the brain stem and higher cortical brain structures to process the sound signals he receives. RN cannot safely process the oral phase of feeding and can only be fed via a NJ tube and will never be able to appreciate texture or taste. His pattern of breathing is secondary to the significant brain stem damage. He has no cough or gag reflex with the result that he cannot protect his lungs from aspiration from reflux of gut contents and aspiration of saliva and secretions. This means that *'his actual 'lung health' will slowly decline due to his neurology'.* Turning to musculoskeletal issues Dr B notes the changes in RN, that he is now prescribed a muscle relaxant to help manage the dystonia. In her view he will *'develop scoliosis with time…as he cannot ever attain normal muscle function, mobility and bone health…This will further impair lung health and musculoskeletal stability. These are all independently additional painful complications'.* She notes also the added complication of RN being on long term ventilation. Turning to higher cognitive functions Dr B notes *'We have no bedside evidence over a longer period during his lifetime in hospital that [RN] has ever experienced higher cognitive functions (i.e. awareness of emotion, understanding of environment, listening to and understanding the meaning of sounds and social cues) and no sign that he has hope to develop them with time…'.* As regards the appreciation of discomfort and the ability to experience pain Dr B considers RN still has some of the basic structures despite his extensive brain injury. As she states *'This means that even though [RN] has deficits in his nervous system that limit his enjoyment of some pleasures of life, he retains the structures that perceive pain and/or discomfort. We can see this clinically in that he has periods when he is settled with no clear evidence of pain, but he can be very unsettled with clear evidence of pain at other times (escalation of heart rate and random thrashing movements in keeping with distress with secretions in between suctions, raised heart rate with invasive cares, dystonic movements with cares).'*

23. In her statement Dr B sets out the second opinion she sought from Dr Y in November 2024, and why she disagreed with him regarding short term ongoing ventilation due to the burdens of continuing that and longer term did not support ventilation with a tracheostomy. Dr B sets out that she considered a palliative tracheostomy, but rejected it as RN lacks the central drive necessary to maintain his own ventilation requirements without the support of a ventilator.

24. In her first statement Dr V concludes as follows *'it is likely that [RN] is unlikely to gain anything for himself apart from existing and being alive with round the clock invasive medical interventions and support. The only possible pleasure he may experience is a possible awareness of light and what is reported by nurses as 'he*

*seems to settle in the arms of family'. On the other hand, there is no doubt that every single intervention has an element of suffering that is very significantly considerable in summation. [RN] is unable to express what he is experiencing in other way in terms of pleasure, but he can show us when he is distressed. Sadly, things will only continue to get worse with time as he will unavoidably and inexorably deteriorate in many of his general health domains…By providing him with long term ventilation we are in effect preventing the natural process of his passing and exposing him to more and more suffering (that he is unable to protect himself from) without the possibility of a natural end'.*

25. Dr B was asked to review RN more recently, on 4 February 2026, due to RN's increasing dystonia. She met RN's parents and discussed the rescue plan to manage this. The plan sets out steps that should be taken dependent on how long the dystonic episode lasts with a staged plan for sedative medication. Dr B saw RN again on 19 February 2026.

26. In her oral evidence she emphasised the need for constant re-evaluation of the dystonia plan and agreed not all episodes required medication. When asked about the parents observing that RN could touch the iPad screen Dr B considered that if RN had the ability to touch the screen he would extubate himself due to the level of discomfort from the ETT. When pressed about the trajectory of the dystonic episodes and that RN appeared more stable, she stated that is at the expense of sedating medication which has an impact on his ability to manage his secretions. She noted that the extent of the recent episodes had required diazepam the previous day. Dr B was concerned that with RN's dystonic episodes now being moderate to severe this increased the risk of gut dystonia, which impacts the ability to absorb food and the need to move to TPN feeding via an intravenous catheter.

27. Dr Taylor, Consultant Paediatric Neurologist, was instructed by the parents. He reviewed the medical records and examined RN on 13 January 2026, being with him for about 4 hours. Due to the severity of his dystonia the previous evening RN had required a dose of IV lorazepam with the mother being with him until 3am. He agrees with Dr B's conclusion that long term ventilation is not in his best interests. RN has no prospect of neurological recovery and he considers it '*wholly unrealistic to expect him to acquire any significant additional developmental skills beyond those he currently demonstrates'.* He describes RN's position as *'his neurological deficits are permanent and non-reversible'.* He considers RN is able to experience pain and recognises that RN appears comfortable and calm with his father watching him but that does not demonstrate true higher cognitive function. He considered it unlikely RN can *'interpret, understand, anticipate, or feel comfort from parental or caregiver reassurance'.* He continues *'It is likely that he lacks the cortical integrity to interpret auditory stimuli in a meaningful way, although he appears to recognise his parents and remains calm in their presence, as seen in videos reviewed'* although considers it *'unlikely that auditory input serves as a consistent or meaningful source of comfort or emotional regulation for him'.* He considers further dystonic episodes are '*inevitable'* and during severe dystonic episodes *'he will experience significant pain and physiological instability'.* He agreed with Dr B regarding the risk of gut dystonia. In his oral evidence he considered RN looking at the iPad as RN having orientated very fleeting. As regards the evidence about the comfort RN appears to get from his parents and what it conveys about RN he considered it is being interpreted with a

degree of hope and he has to look and consider the wider clinical picture and it does not demonstrate higher cognitive function.

**Respiratory**

28. Dr Z, Consultant in Paediatrics and Paediatric Respiratory Medicine, had recently taken over RN's respiratory care from Dr A. He examined RN on 5 February 2026 for about 30 – 45 minutes. He noted that RN did not have a consistent respiratory drive with periods of apnoea post dystonia or sedation. He notes that since August 2025 RN has received eight separate courses of antibiotics for infections. He describes RN's recent RN ray as showing a persistent right lung collapse, hyperinflated right middle lobe and abnormalities in the perihilar region of the lungs. He concludes that RN's *'lack of ability to derive benefit, enjoy or appreciate the benefit of continued life. Therefore, life sustaining intervention in the form of ventilatory support both in an intensive care setting or with insertion of a tracheostomy and ventilator are not in RN's best interests.'* In his oral evidence he considered the recent increase in RN's dystonia would exclude any consideration of RN being discharged from hospital.

29. Prior to Dr Z's involvement he had been under the management of Dr A who in May 2024 sought a second opinion from Dr G, who advised consideration of a tracheostomy in order to mitigate the damage caused by the current interface. At that stage RN was on non-invasive ventilation (NIV) and there was concern about severe midface hypoplasia secondary to his NIV mask. In his letter Dr E stated *'With a more stable airway, if [RN] still demonstrated respiratory instability, this would be a stronger indication that he is not a candidate for invasive long-term ventilation. I am also taking into consideration the fact that both the clinical team and the family have expressed the desire to have [RN's] outcome debated in court. This is likely to take some time while [RN's] face continues to deteriorate. My concern would be that continued non-invasive ventilation will be contributing to his suffering therefore, in the short-term [RN] could be a candidate for invasive tracheostomy ventilation. If a decision is then reached that palliation is ultimately the best course of action for this young man, this can be achieved with him receiving invasive ventilation in hospital or in the home setting'.*

30. This was considered at a meeting of the National Long Term Ventilation Advisory Group (NLTV) in June 2024 which is a group attended by LTV consultant representatives from eight UK centres. This NLTV is chaired by Dr Z. Dr Z said he understood the parents were aware RN's situation had been referred to the NLTV. The parents say they were unaware of this. He agreed if they have not been informed they should have been and plans in the future to revise their arrangements so any referral should confirm the family have been informed. The NLTV was set up during Covid and has continued to meet since then as an advisory group to help decision making in these difficult cases. Dr E also attended that meeting and is recorded as stating that due to the severity of the midface hypoplasia and the concerns over a lengthy court delay that a tracheostomy '*should be considered in the interim'*. The record continues *'On this point the collective opinion was not in favour of a tracheostomy insertion however it was understood why this should be considered. Consideration for intubation to relieve discomfort whilst awaiting a court decision should also be considered'.* Dr A took RN's case back to the NLTV in January 2025 when RN was stably intubated and ventilated on PICU to ask whether any LTV

service would offer tracheostomy ventilation. Dr E is recorded as stating that a court would be best placed to help this decision. The summary records there was no centre at the meeting that would offer long term tracheostomy ventilation. The record of the meeting notes '*This has left a decision to be made with regards to the appropriateness of a tracheostomy with a limitation or ceiling of care not involving ventilation not involving ventilation or a palliative extubation and comfort support. It has also been demonstrated that long term 24hours/day NIV support is not something that can be facilitated. We shall await the outcome of the court review'.*

31. Dr E's further opinion was sought by Dr A in September 2025 when he concluded that tracheostomy-LTV should not be offered, due to RN's severe neurological injury.

32. In her statement Dr A rejects LTV for RN via a tracheostomy as it was not an option being offered by the Trust or any other LTV centre. It is intended for children who have the potential to achieve a quality of life with LTV that they would not otherwise be able to enjoy. It is not intended to prolong the life of a child whose brain is so severely damaged that they are unable to interact with their surroundings, enjoy the benefits of life or even breathe for themselves. The burdens of this on the child and the family are high and should not be placed on a child who has no ability to benefit from it. Dr A considers that due to RN's condition he would only experience the negative consequences of tracheostomy-LTV without any potential to take pleasure from life experiences, or interact with the world around him. The option of a tracheostomy as a one way wean was discussed with the parents, which they were unable to agree to. The possibility of a very slow wean was discussed with the parents but agreement was not reached. Dr A does not consider this to be an option now due to RN's abnormal respiratory drive, particularly during times of illness, makes it unlikely that he would survive for a significant length of time with a tracheostomy, and that the risks and burdens of inserting a tracheostomy outweighs any benefits. Having a tracheostomy puts a child at a high risk of contracting frequent respiratory infections and RN does not have the respiratory drive to be able to survive such an infection. The frequent tracheal suction that would be needed is uncomfortable as are the frequent tube changes that would be required. Dr A did not consider that the small amount of time RN would be likely to survive with a tracheostomy alone would be outweighed by the risks of the surgery to insert it and the ongoing burdens of it. Dr A concludes that compassionate withdrawal of ventilation and palliative care is in RN's best interests. She recognises RN appears more comfortable intubated that he did on NIV, his life is *'punctuated by discomfort and suffering, which is not relived by any ability to take pleasure in the world around him. A life in which the best that can be said is that he does not appear to be actively uncomfortable when held by his parents, is not a quality of life that should be prolonged by any burdensome medical interventions'.*

33. Dr E went to visit RN on 11 February 2026 and having considered the updated information he concluded that he did not consider RN *'can breathe on his own sufficiently to sustain life without considerable interventions which are painful and invasive and not in [RN's] best interests'* and agrees that RN's best interests are to have invasive ventilation removed. In his oral evidence he confirmed he did not support a tracheostomy as being part of any palliative pathway. He did not support LTV at home, considering it would be unrealistic in particular as medical advice and support would need to be on hand to support the dystonia.

34. Dr Rosenthal, Consultant Respiratory Paediatrician, was instructed on behalf of the parents. He visited RN on 2 January 2026 and met the parents and the clinical team caring for RN that day. His report supports the application made by the Trust. He did not support a tracheostomy, stating that is a line in the sand as there needs to be a decision about LTV first. He was critical of the delays that had taken place and that RN had been lost sight of. In his report he uses strong language to describe intensive care, describing it as *'cruel and barbaric'*. In his opinion section he described the circumstances in this case as *'the most ghastly and tragic mess I have ever had the misfortune to become involved with'.* Mr O'Brien KC, on behalf of the parents, challenged him about the use of such language in a case like this and what consideration he had given to the impact of that on the parents. Dr Rosenthal sought to justify his use of language to convey the strength of his view as to what had occurred in this case. It was clear through his answers that he displayed no insight into how he expressed himself in his report would impact on the parents. It demonstrated, in my judgment, a complete lack of judgment regarding the sensitivity of the situation. The mother's oral evidence about the distress she felt on reading Dr Rosenthal's report was powerful. She said she felt what he said was critical of how RN's parents had behaved in making decisions about RN.

### Intensivist

35. Dr C, Consultant in Paediatric Intensive Care, has cared for RN routinely, seeing him and being responsible for his care about one week in eight, and when he has been on-call overnight. He confirms the attempts to wean RN's level of respiratory support have been unsuccessful and in his opinion RN is dependent on mechanical ventilation and will never be able to breathe independently for a sustained period. He recognises that they have not been able to reach agreement with RN's parents as to what is in his best interests. He reports on his physical examination of RN which accords with the examinations undertaken by others. He reports that the nursing staff who regularly care for RN believe he shows response to louder noises which can induce more physical movement. In response to what would typically be reported as painful or uncomfortable stimulation RN demonstrates an increase in spontaneous non-purposeful movements of his limb and head, can become more stiff that usual and display an increase in his heart rate. In his view, and that of the nursing team, RN can experience pain. He agrees there is no evidence of any cognitive awareness of his environment. He reports that nursing staff have suggested that when he is agitated he can appear to settle in his parents' arms. He reports that RN spends periods in his chair and in his view only benefits minimally from those episodes. In his oral evidence he provided an update regarding the dystonia, stating he had had 12 significant dystonic episodes since the previous day with back arching, limb movements, increased heart rate, blood pressure and was red flushed. Between 7.30 am and 9am he had dystonic episodes with only a short break. RN was given two extra doses of the rescue therapy to try and break the cycle. He agreed with Ms Cavanagh KC that there has been a decline in RN's overall baseline with frequent infections due to long periods of intubation.

36. His opinion is that RN *'has sustained a very severe brain injury with no prospect of recovery. It is my opinion, on the balance of probability, that he experiences pain and discomfort but has no cognitive awareness of his environment or of those around him.*

*[RN] has significant chronic lung disease and is dependent on mechanical ventilation; it is my opinion that he will never be able to breathe independently for any sustained period. [RN] will always be dependent on artificial feeding.'*

37. Dr C considers RN's clinical situation meets the criteria laid down by the RCPCH where treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit. In particular *II A 'Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits'; II 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'* and arguably '*II 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'.*

38. In summary, Dr C considers the burdens are associated with his underlying condition (such as dystonia), routine nursing interventions can trigger dystonia and if future ventilatory support is continued there will be additional burdens associated with his underlying illness caused by immobility, breathing difficulties and respiratory failure, bone disease and scoliosis with associated cardio-respiratory impairment. There are also the burdens of the continuing treatment he requires such as the ETT, suctioning and repeated replacement of a NJ tube.

39. He considers due to the severity of his brain injury RN gains no apparent enjoyment from any aspect of ongoing life and cannot benefit from ongoing mechanical ventilation.

40. As regards the issue of delay in his statement he refers to the collaborative approach between the clinical team and the family in these difficult cases and they often achieve a consensus. He states *'From the time that it is decided that a judicial path will be followed, the delays encountered are variable.'*

41. Dr Brierley, Consultant Paediatric Intensivist, provided a report on behalf of the parents. He visited RN on 16 January 2026 and spent time with RN, his parents and the clinical team. He placed RN on a Swedish nose, a device that enables him to be disconnected from the ventilator and to breathe spontaneously, which he did for around an hour. He was not clear what caused him to be re-connected to the ventilator again. As a result he considered RN had good respiratory drive and minimal current effects from lung disease but would be very unlikely to survive for a prolonged period if he was extubated. Whilst Dr Brierley agreed RN is loved by his parents and the ventilation is keeping him alive but he considers RN shows no objective signs of pleasurable interaction with the environment or cognition related to this. He may react to noise but it is uncertain and his parents consider he does react to videos but there are no objective reports of enjoyment. Dr Brierley recognises the quality of someone's life is subjective he cannot see in RN's situation how he can have any positive experience and there are undoubted burdens associated with his existence. He concludes that there should be a one way wean of invasive mechanical ventilation. He sets out that he did consider a one way wean to NIV and then re-assessment but concluded that given RN's previous levels of care it is unlikely he would ever be a candidate for discharge home. This is due to his prior dependency, frequency of

suctioning and physiotherapy, lack of airway protective reflexes and unilateral vocal cord palsy as well as the management he requires for dystonic episodes. Dr Brierly confirmed in evidence this was after having read the detailed medical records, in particular regarding the management of the dystonia.

**RN's parents**

42. RN is the youngest in a large family with siblings ranging from 8 – 22 years old. His parents have been at his bedside since he was born. They visit each day, often separately, so he has one of them there whilst the other is caring for the rest of the family. RN's siblings can and do visit and arrangements have been put in place for them to all be together for special occasions, such as RN's recent birthday.

43. In their written and oral evidence his parents describe what they have seen. How RN is comforted by them. His mother described the way he cuddles into her and tends to fall asleep in her arms. She tends to be more quiet when she visits him, will have some nursery rhymes on and will sit with him holding him or dancing with him. He grasps hold of her finger. She considers he watches the iPad when it is on, has put his hand out to fast forward it and his eyes are focussed. The most recent video she said shows him in his P pod chair watch the iPad. She described how RN can sit in the P pod chair for up to four hours, the nurse disconnects the tube and the parents lift him and strap him in then he is reconnected back to the ventilator. She has observed his heart rate go down when he is settled in the chair. When asked why this has not been observed by others she said she is there all day.

44. The parents are clear they did not know RN was being referred to the NLTV in June 2024 or January 2025. The mother described that having been told the Trust were going to make an application to court, and delayed in doing so, made her feel isolated. She felt the doctors were avoiding them.

45. In early February 2026 the mother had an eye infection and was not able to visit RN. She described how hard she found that and her excitement when she was able to go in again. RN's dystonia was bad and she found it hard as she did not want to touch him in case it was painful or distressing for him.

46. In her statement and oral evidence the mother described what she wanted, stating she wants to get him home and considers a tracheostomy and a portable ventilator as the best way to do that. She considers she would be able to manage a care plan at home. She has managed some huge upheavals in the last few years. She described how distressed she felt when she read the language used in Dr Rosenthal's report. She felt the description he gave was aimed at her.

47. The father's oral evidence gave a powerful description of his love for RN, describing him as the spotlight in the family. He considers RN knows he is there, if he touches him he moves his head. He wants to do the best for RN until nature takes him. He described himself as doing his job as a parent and will not give up on his hope and dream that RN will get better. He considers that the opinions are different from their experience.

**Children's Guardian**

48. The Guardian visited RN twice, and saw the parents and clinical team on each occasion. On the second visit she spent the day at the hospital. In her report she sets out the detailed discussion she had with the parents and her observations of RN. She described RN as a beautiful boy who is evidently loved by his parents and family. His parents have advocated for what they consider to be in his best interests. Despite RN physically growing he has not met any developmental milestones which is contributed by the profound and irreversible brain injury. She acknowledges the parents reporting of RN meaningful engagement and interactions, this has not been the observations of the treating clinicians. She notes the nursing staff have observed RN does appear more settled when his parents are present which is an indication that he is able to experience some pleasure. During her second visit the Guardian observed RN experience dystonia. She notes it is agreed by the parents and clinicians that these episodes cause RN to experience pain and discomfort and they are increasing in severity and frequency which are contributing to an overall progressive deterioration in RN's health. The Guardian considers the medical evidence from the clinicians and the experts agree that the continuation of short and long term ventilation is not in RN's best interests considering the pain and suffering he is experiencing. The same considerations apply to the parents' proposal of a tracheostomy and portable ventilator. Her assessment is that that despite the medical treatment and interventions keeping RN alive, he does not derive benefit from this.

49. In her oral evidence the Guardian said that RN's lived experience is all medical intervention that is not going to change the outcome for him. Mr O'Brien pressed her about the parent's evidence about their observations of RN (such as him turning towards them when they go in the room, gripping his mother's finger, watching the iPad) which if accepted would it change her conclusion. The Guardian said she had already factored in what the parents have described as well as the clinicians. She said she had considered the improvement noted in RN following the revised rescue plan, her concern was that the underlying risk that the dystonia was going to get worse. She agreed the language used by Dr Rosenthal was insensitive.

## Legal framework

50. There is no issue about the legal framework between the parties.

51. The most recent exposition of a summary of the relevant principles was set out in the judgment of Mr Justice McKendrick in *An NHS Foundation Trust v (i) J (By his Children's Guardian), (ii) A Council and (iii) FP (By her litigation friend the Official Solicitor)* [2025] EWHC 2247 (Fam):

> "37. The law in the area of serious medical treatment for children is clear and settled and I rely on the summary of the law set out in Mr Hallin's helpful skeleton argument. Where a parent is not willing to exercise parental responsibility to sanction the medical treatment (or its withdrawal), the court has the ultimate power to require treatment to be given, in accordance with a 'best interests' test. In considering such an application the Court must weigh up the advantages and disadvantages of providing or withholding the various treatment options within that plan, and to balance them in order to determine where the child's best interests lie (*Re J (a minor) (wardship: medical treatment)* [1991] 2 WLR 140; 3 All ER 930; [1990] 2 Med LR 67).

38. The court's approach to the child's best interests will necessarily be highly fact-specific and the courts have been slow to set definitive guidance on how to approach the 'best interests' test in this context. For example, in *NHS Trust v MB* [2006] EWHC 507 Holman J said at paragraphs 106-107:

"…this is a very fact specific decision taken in the actual circumstances as they are for this child and today… My sole and intense focus has been this child alone".

39. Macdonald J has provided a helpful summary of the legal principles in *Manchester University NHS Foundation Trust v Fixsler & Ors* [2021] EWHC 1426 (Fam):

"56 The court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place, on the grounds that it is in the child's best interests (see *In re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement between those with parental responsibility for the child and those treating the child (*An NHS Trust v MB (A Child Represented by CAFCASS as Guardian Ad Litem)* [2006] EWHC 507 (Fam); [2006] 2 FLR 319). The court has no power to require doctors to carry out a medical procedure against their own professional judgment.

57. As I have observed in previous cases, the legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not "Gillick" competent is well settled. The following key principles can be drawn from the authorities, in particular *In re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 , *R (Burke) v General Medical Council (Official Solicitor intervening)* [2005] EWCA 1003; [2006] QB 273 , *An NHS Trust v MB*, *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181; [2005] 1 WLR 3995 , *Kirklees Council v RE* [2014] EWHC 3182 (Fam); [2015] 1 FLR 1316 and *In re Gard (A Child) (Child on Life Support: Withdrawal of Treatment)* [2017] EWCA Civ 410; [2018] 4 WLR 5 :

i. The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.

ii. The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.

iii. The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term "best interests" is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt (Southampton NHS Trust intervening)* [2004] EWHC 2247 (Fam); [2005] 1 FLR 21 at [21] should be recalled: "This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."

iv. In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.

v. There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.

vi. Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.

vii. There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.

viii. Each case is fact specific and will turn entirely on the facts of the particular case.

ix. The views and opinions of both the doctors and the parents should be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *In re A (A Child)* [2016] EWCA Civ 759; [2016] Med LR 427 at [34] , said as follows: "The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly

> irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

x. The views of the child must be considered and be given appropriate weight in light of the child's age and understanding."

40.These principles have been reiterated at appellate level. In *In re A (A Child)* [2016] EWCA Civ 759; [2016] Med LR 427 the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 at para 22 , namely:

"Hence the focus is on whether it is in the patient's best interests to give the treatment rather than 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 they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

And at para 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 towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

41.In the case of *Gard*, McFarlane LJ (as he then was) reiterated, at para 112 that:

"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."

42.Whilst Article 2 of the ECHR is plainly engaged where life and death medical decisions are in question, there is no obligation to provide treatment that is assessed as being futile. In *An NHS Trust A v Mrs M and An NHS Trust B v Mrs H* [2001] 1 All

ER 801, it was held by Dame Elizabeth Butler-Sloss, then President of the Family Division, that:

> "Article 2… imposes a positive obligation to give life-sustaining treatment in circumstances where, according to responsible medical opinion, such treatment is in the best interests of the patient but does not impose an absolute obligation to treat if such treatment would be futile."

**Submissions**

52. On behalf of the Trust, Mr Karim KC recognises the presumption to preserve life. In this case, he submits, it is rebutted in circumstances if the ongoing treatment has no prospect of success or is futile. He groups the medical evidence under three headings, namely (1) Neurological; (2) Respiratory; and (3) Intensivist. The medical evidence under each heading is not challenged. He relies on Dr B's evidence in particular for setting out the extent of the brain injury and the consequences for RN regarding matters such as RN's vision, hearing, breathing, feeding, musculoskeletal, cognitive functioning, appreciation of discomfort and ability to experience pain. He submits the medical evidence establishes there is no prospect of neuro-recovery. He acknowledged the evidence from the parents that RN can experience comfort from them and RN's eyes may follow his parents. He relies on Dr B who said she hoped that might be the case but clinically and neurologically may not be possible. Turning to the evidence regarding RN's respiratory condition, he aligns himself with what has been described as unfortunate and disappointing language used by Dr Rosenthal. Both Dr Rosenthal and Dr Z conclude that due to the extent of the brain injury and RN's respiratory drive not improving and there being no potential for improvement the continued ventilation of RN with all the burdens that go with that should not be continued. Both intensivists agree that RN experiences pain and he submits the evidence demonstrates that the clinical situation meets the criteria laid down by the Royal College of Paediatrics and Child Health.

53. On behalf of the parents, Mr O'Brien, emphasises the breadth of matters the court should consider when looking at best interests, relying on the summary recently set out in the judgment of McKendrick J in *An NHS Foundation Trust v (i) J (By his Children's Guardian), (ii) the Council and (iii) FP (By her litigation fiend the Official Solicitor)* [2025] EWHC 2247 (Fam) at [37] – [42] emphasising that the medical evidence is but part of the evidence the court needs to consider. The parents' evidence, he submits, was profound and demonstrated their enormous love and commitment to RN. He is the centre of their life and submits this has not been fully taken account of by the medical evidence, in particular Dr Rosenthal through the use of language used by him in his report. This is a hugely committed family who have watched RN grow. He submits insufficient regard has been given to what RN's life means to him and those around him. For RN he enjoys the comfort derived from his parent when he is distressed or unsettled, that is a benefit in these circumstances. The love of a parents comforting a child who is distressed. The parents have described the enjoyment RN gets from watching the iPad and describe how RN recognises them and gets enjoyment from sitting in the P pod chair, his father bathing him and his mother placing her finger in his hand. He submits these are factors based on what the parents experience from the time they spend with RN. The benefits that could be

gained from being out of the hospital and in the community, as described by Dr Y, should not be ruled out. There is evidence that RN's respiratory function is relatively good from Dr Brierley's evidence. Mr O'Brien submits RN's breathing and his quality of life have not been properly tested. RN's dystonia is now more stable. He submits the court should refuse this application and re-evaluate whether a tracheostomy should be done with the option of a discharge home. He acknowledges it will require a complex plan but the parents are committed to making that work.

54. Ms Cavanagh accepts the parents have a valuable perspective to bring when looking at the benefits for RN, which includes the inherent value in life itself. The parents are here to fight for RN and want what is only best for him. What they have seen, over RN being comforted by them and being startled by loud noise, have not been observed by others over an extended period of time. She relies on what Dr V said that if RN did have purposeful movement she would expect him to seek to move his ETT. There are no observations of him doing that over an eighteen month period. Ms Cavanagh submits RN is suffering and his clinical position is declining. Any stability observed is through sedation. The position regarding RN's dystonia means there is a real risk of gut dystonia. The complexity of RN's position with his medical and care needs means that any discharge home is not possible.

## Discussion and decision

55. These cases are the most difficult. They require the court to carefully analyse and evaluate the evidence considering the unique value in human life, the child's quality of life and sensory stimuli, the extent to which the treatment is invasive and distressing, the details of any prognosis and whether the treatment continuing could lead to some improvement.

56. RN is the centre of a large loving family. There is no question that RN's parents are devoted to him. The many videos seen by the court demonstrate that in a powerful way. His parents have visited him every day, often more than once and have been committed to supporting the clinical team in meeting his daily care needs. They described the importance of their religious beliefs and how they have been supported by regular visits from the hospital chaplain. In their evidence both RN's parents powerfully described their love for him, how he has kept on fighting and how strongly they feel they should fight for him. They were deeply hurt by the language used by Dr Rosenthal in his report. In their evidence and in their discussions with each of the experts and the Guardian they have described how they see how RN reacts to their presence and when they undertake caring tasks for him, when the iPad is on and when he is in his P pod chair. They emphasise that they are there for extensive periods of time with RN and what they have observed should be weighed in the balance when considering what is in RN's best interests. The nurses have observed that when RN is unsettled he is comforted and settled by his parents. His mother movingly described how RN cuddles down into her and how his father helps settle him. RN has also been observed to react to loud noises. Apart from in those two respects, what the parents have observed and describe is not supported by any other clinical observations over an extensive period of time. RN has been in PICU since July 2024 with 1:1 nursing support and if such reactions were taking place they would have been seen by others who are also with RN for extended periods of time. As Dr B observed, if RN did have

any purposeful movement she would expect him to seek to remove his tube, which he hasn't.

57. The detailed medical evidence in this case is not in issue regarding RN's underlying medical condition. The clinical evidence has been the subject of scrutiny through the instruction of independent experts on behalf of the parents. That evidence confirms that due to the extensive brain and brain stem injury RN suffered at birth the consequences of his underlying disease are significant and include the following matters. He has no effective gag reflex, cannot swallow or clear his own secretions. He is unable to breathe independently due to the extent of his brain stem dysfunction and will remain dependent on mechanical invasive ventilation. He does not track or fix with his eyes, and has no purposeful vision. Oral secretions are significant as his bulbar dysfunction is at the most severe end of the spectrum which, in turn, has an impact on the management of his respiration. These secretions have an impact on his skin integrity and he is at risk of pressure sores. He is at high risk of recurrent respiratory infections, they have recently increased and the infections become more antibiotic resistant. He does not spontaneously move all four of his limbs and there is no purposeful movement. He is likely to develop scoliosis and spinal deformity which will complicate his respiratory drive and bulbar dysfunction. The increase in dystonic episodes have been both in terms of frequency and severity which causes him pain, distress and discomfort. They can be triggered by relatively small events, such as touch, and result in increased heart rate and temperature. There is a real risk this could develop into gut dystonia which would have an impact on his feeding. He is fed via an NJ tube which requires regular changing and maintaining. Due to the extent of his brain injury he has significant microcephaly and makes no meaningful developmental progress.

58. It is not in dispute that RN can experience pain. This is experienced by him in a number of different ways including from the day to day care, such as the daily replacement of tapes to secure his tubes and the regular suctioning required to clear his secretions. Suctioning can be every 15 minutes if RN has an infection, otherwise every 30 – 60 minutes. It is also experienced during the dystonic episodes that have increased in number and severity and can be caused by physical contact. The rescue plan and adjustments in medication, in particular the increase in sedation, can alleviate the pain and discomfort but have the secondary effect of sedating RN thereby reducing his experience from any comfort from his family. Being fed by an NJ tube requires the tube to be changed with discomfort and it can become dislodged. He will require mechanical ventilation long term which involves regular changes of his ETT requiring sedation to manage the pain and discomfort. The recurring infections and the pressure associated with ventilation damage his lungs. RN has difficult IV and long line access, they will need replacing and have an ongoing risk of infection. His skin integrity risks require frequent assessment and for him to be repositioned which as he prefers lying on one side can cause distress and risks dystonia.

59. Due to the nature and severity of RN's brain damage it is very difficult to assess how RN perceives his position. The presumption of life; the sanctity of life is important. RN has shown himself to be a fighter. His parents have been told on many occasions he would not survive, but he has. He is surrounded by the unconditional love of his family, the daily presence of his parents, their prayers and is comforted by his parents

when he is unsettled. The reactions they describe, such as some recognition when they arrive that have not been seen by others, should not be discounted and is factored in as a possibility as they are very attuned to RN's needs. Although he is ventilator dependent his respiratory drive was good for a short period as Dr Brierley observed. The parents wish for RN to receive a tracheostomy and possibly facilitate a move home with the potential benefits that could bring. That needs to be considered in the wider medical context of the risks of that tracheostomy procedure being done and the likelihood of the support required being available. Whilst not doubting the obvious commitment and dedication of these remarkable parents the reality now is that due to the complexity of RN's medical position, in particular the repeated infections and the level of dystonia with the need for specialist medical advice to be on hand, such a plan is very unlikely to be possible and would have a very high risk of RN returning to hospital in a short period of time.

60. Having considered the evidence the court must remain focussed on what is in RN's best interests. His welfare is my paramount consideration. The evaluation of his best interests has a broad canvas and includes his medical, emotional and all other welfare considerations and the court must conduct a balancing exercise weighing all the relevant factors. It is not a mathematical exercise but it is an objective one.

61. The medical evidence is united as to the extent of the injury to RN's brain and brain stem and the consequences for RN of that. He will not improve. He will continue to deteriorate both in terms of the physical consequences and risks for him (such as scoliosis), the need to remain on mechanical ventilation long term and the very high level of intervention required to meet his day to day needs. He will continue to experience pain (evidenced by the increase in his heart rate and appearance) from the frequent interventions and the dystonia. The pain can be managed by medication but the increasing levels required makes it likely that he will be less aware of any comfort derived by him from his parents' presence.

62. In the final analysis of RN's best interests the characteristics of RN's position caused by the irreversible brain damage and its consequences for RN, which are likely to increase, weigh heavily in the balance against the benefits the parents rely on in the continuation of RN's current treatment, in particular the preservation of life and RN being able to continue to benefit from being part of their loving family. I have carefully weighed the parents' strongly and genuinely held views against the burdens of continuing the treatment, the presumption to preserve life, the impact on their right to family life and the importance of their religious beliefs.

63. In my judgment, having undertaken that balance, it is not in RN's best interests for life sustaining treatment to continue. I will make the declarations sought by the applicant.