



Neutral Citation Number: [2021] EWHC 2377 (Fam)

Case No: FD21P00513

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**  
**IN THE MATTER OF THE SENIOR COURTS ACT 1981**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 25/08/2021

**Before:**

**THE HONOURABLE MR JUSTICE COBB**

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**Between:**

**GUY'S & ST THOMAS' NHS FOUNDATION  
TRUST**

**Applicants**

**ROYAL BOROUGH OF GREENWICH**

**- and -**

**M (mother)**

**Respondents**

**By her litigation friend, C**

**F (father)**

**By his litigation friend, C**

**R**

**(A child, by Lynn Magson, Cafcass, as his Guardian)**

**Caroline Hallissey** (instructed by **Bevan Brittan LLP**) for the Applicants

The First and Second Respondents were not present but their Litigation Friend, C, attended the hearing, supported by his uncle, U, albeit they were unrepresented

**Arianna Kelly** (instructed by **Cafcass Legal Services**) for the Third Respondent (child)

Hearing date: 19 August 2021

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**Approved Judgment**

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**THE HONOURABLE MR JUSTICE COBB**

This judgement is being handed down in public on the strict understanding that the anonymity of the child, the members of his family (both biological and foster), the treating health and social care professionals, the professionals providing second opinions and the institutions that the child is, has or will receive care at, must be strictly preserved. Attention is drawn to the terms of the injunction referred to in paragraph [5] of the judgement. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

## **The Honourable Mr Justice Cobb :**

### *Introduction*

1. R is 14 years old. He is a young man whose carers describe as “brilliant” and “capable of many things” who, until recently, “had a full and enjoyable life”. He is said to be an “active participant” in school, where he appears to have benefitted from attentive and skilled care and where he is said to be “much loved”. He is sociable and has a strong sense of humour, which he has displayed even recently in the extraordinarily challenging circumstances which I describe below; he has enjoyed many simple pleasures in life, including singing, swimming, watching cartoons, children’s programmes, and cricket. He has some favourite soft toys he can hold under his arms. It is for all these qualities and endearing characteristics that R will forever be remembered by those who hold him in their affections.
2. Tragically, R also has profound and multiple medical needs and disabilities; these have affected him all his life. He is currently in the Paediatric Intensive Care Unit (PICU) of a hospital in London, and is in a critical medical state. Having suffered a respiratory collapse three months ago, it now appears that he is entirely dependent on invasive intubation ventilation.
3. An application has been made on 30 July 2021 jointly by Guy’s & St Thomas’ NHS Foundation Trust and by the Royal Borough of Greenwich by which they seek the court’s authorisation to take action to extubate R, having reached the reluctant conclusion that they have done all that they can to wean him off his ventilator without success. They are further of the view that long-term ventilation is not in his interests. It is acknowledged that the likely consequence of extubation is that this will bring R’s life reasonably swiftly (within a matter of days) to an end.
4. Permission was granted to bring this application by Lieven J on 2 August 2021. R was joined to the proceedings, and is represented by a Children’s Guardian, Lynn Magson, appointed by Cafcass. The First and Second Respondents (M and F) are R’s parents. F has learning disabilities and M suffers from mental ill-health; they have both been assessed to lack capacity to litigate, and on the evidence which I have read in this case there is reason to believe that they do not have capacity to consent to treatment of R. They participate in these proceedings by their litigation friend, C, who is their nephew (R’s cousin), and their carer. C has often acted as a facilitator in communication between the parents and the social work team; C was assisted in his role as litigation friend at the hearing before me by U, a maternal uncle. The Local Authority funded some legal assistance for the parents; they are not legally represented before me. They have had very limited contact with R over the last three years, but saw him briefly less than one month ago, in the context of this application.
5. This final hearing was set up by Lieven J. She permitted second medical opinions to be informally obtained. I now have the benefit of reading that second opinion evidence; given that these opinions have been given otherwise than under *Part 25 FPR 2010* I propose to afford these ‘second opinion’ experts and the clinicians and social worker (and of course the family) anonymity in this judgment. This level of anonymity is supported by counsel. A Reporting Restriction Order has been applied for and an order granted.

### *Background*

6. R was born very prematurely (at 27 weeks gestation) in 2006 to consanguineous parents. Within months he was noted to suffer global developmental delay and cerebral palsy. MR scans show that he suffers from leukodystrophy; he has seizures for which he receives anti-convulsant medication. He has an unsafe swallow and generates thick secretions in his airways. He is completely gastrostomy fed by PEG<sup>1</sup> tube. He is wheelchair dependent, and has poor vision and communication skills.
7. R was accommodated by his parents when he was three years old, and *Part IV Children Act 1989* care proceedings followed, based upon wide-ranging concerns about the parents' low level of understanding of R's profound and exceptional needs, and their inability safely to care for him. At the time of the Local Authority's application R's birth parents had increasingly disengaged with the Local Authority and professionals involved in R's care, and did not make themselves available to provide the necessary consents for the required tests and surgery. In 2012, R was made the subject of a care order in favour of the Royal Borough of Greenwich.
8. Supervised contact between R and his parents has been infrequent despite the support offered to facilitate this, as it appeared that M did not wish for contact. Face-to-face contact last took place in 2018; at that stage M displayed a continuing lack of appreciation of R's very considerable needs (she tried to make him stand up, which was well beyond his capability); contact reverted to indirect only. The parents have in fact seen R very recently, and there is a plan that they should see him again very soon.
9. R has lived for the last eight or more years with long-term foster carers. They have provided him with exceptional care; recently, they were exploring the option of adopting R. They have amply earned my most heartfelt respect for the evidently superlative care, and the love, which they have shown to R over many years.

### *R's medical condition*

10. From an early age (around 9 months), it was realised that R was suffering from a range of profound medical difficulties attributable at least in part to his extreme prematurity. On closer assessment, he was found to suffer from suspected mitochondrial cytopathy, leukodystrophy (leukodystrophy is a well-recognised sign of severe mitochondrial disease, and, I am advised by the medical experts, cannot be cured), global developmental delay, and dystonic movement disorder. He has neuromuscular scoliosis, bilateral spastic dystonia, and epilepsy. As indicated above, he is PEG fed. In recent times, he has developed seizures which required admission to his local hospital and for which he was prescribed regular anti-convulsant therapy. In the last year, he has developed progressive obstructive sleep apnoea which required institution of home oxygen at night. Despite his young age, he is well known to the metabolic, respiratory and neurology medical teams of the Applicant Hospital Trust.
11. There are no effective treatments for mitochondrial disorders. There is no treatment available to reverse the longstanding neurological damage which has already occurred. Sadly, children with complex co-morbidities like R have a limited life expectancy.

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<sup>1</sup> Percutaneous Endoscopic Gastrostomy

12. When R is well, he is interactive and can make his needs known by using eye pointing and gesturing. He can say "oh man", smiles, giggles, kisses and is very interactive. As I have indicated above (§1) he has enjoyed a quality of life, which was expanding even recently with his use of the technology offered by 'Eye Gaze'.
13. Earlier this year (May 2021), R became acutely unwell, and suffered respiratory failure, secondary to his underlying mitochondrial disorder. He was struggling to breathe. He became unresponsive. He was resuscitated and conveyed by ambulance to his local hospital where he was intubated, and transferred to another specialist PICU in London before being subsequently transferred to the current specialist PICU in London. For much of this time, he has required invasive ventilation with an endotracheal tube (ETT) in a PICU setting to sustain his life. He has been in and out of the PICU, on occasion staying for a prolonged period; four attempts at extubation have been attempted without success. On 3 July 2021 he was admitted again onto the PICU following an acute deterioration where he remains. He has ongoing issues with copious and thick secretion load and had palliative ligation of his salivary ducts on 21 July 2021 to control this. He is currently breathing on the ventilator with minimal support. There are risks to maintaining him in his current situation, namely hospital acquired pneumonia and increasing respiratory and skeletal muscle atrophy and weakness. The treating team recommend extubation followed by palliative care only. Dr. A (his clinical paediatric metabolic consultant) reports:

“I do not consider that [R] will recover from this episode. Unfortunately, [R]’s presentation represents the end stage of his condition. ... In summary, [R] has presented with a severe leukodystrophy that is highly likely caused by a mitochondrial disorder. He has demonstrated a long period of stability, but progression of his disease is evident in his current situation. ... there are no effective treatments for mitochondrial conditions and certainly no options to reverse the longstanding neurological damage already accrued.”

14. The decline in R’s condition this year is believed to represent end-stage deterioration in his mitochondrial disorder; he experiences significant upper airway secretions which cause airway obstruction. This is compounded by increased chest secretions which he is unable to clear by coughing or swallowing; because of muscle weakness and dystonia he has difficulty in maintaining his airway at the back of his throat. He is very susceptible to chest infections. The clinicians are of the view that his life expectancy with continued ventilation is likely to be a matter of months rather than years. Taking into consideration all the underlying clinical factors, and the trajectory of R’s condition during this admission, even with invasive ventilation and treatment, his life expectancy may be as short as a few weeks.
15. After much careful consideration, the clinicians caring for R are of the view that they have taken all possible steps to maximise the chances of R being successfully extubated. It is felt that this is now a particularly optimal time to perform the extubation (according to Dr. B, another of the treating clinicians and a PICU consultant) because:
  - i) R is at an optimum level of health to manage the extubation, as he is currently stronger and free of infection;

- ii) He has undergone the salivary gland ligation and had exhausted treatment options to manage secretions;
- iii) R is currently requiring only minimal support through the ventilation being provided;
- iv) It is felt that his baseline condition will worsen over time. There is no prediction by any clinician involved in his care that he may recover beyond his current condition;
- v) He could be extubated in a calmer, less stressful environment, which in Dr. B's experience leads to better outcomes for the child and would likely result in him surviving for a longer period without ventilation.

If the extubation is not successful (and the likelihood is that it will not be successful, and that he is unlikely to survive for more than 2 weeks) it is the clinicians' clear view that it would not be in R's best interests for him to be reintubated, nor to receive other invasive treatments for deteriorations arising out of his underlying conditions. The treating team have clarified that non-invasive ventilation and suctioning is not likely to be effective for R; attempts to wean R from invasive to non-invasive ventilation have not succeeded, in the view of the treating clinicians on account of his muscle weakness, atrophy and dystonia.

16. A tracheostomy has been considered. Dr. B opines:

"The multidisciplinary team does not consider that it is clinically appropriate to place a tracheostomy. The tracheostomy tube is more rigid than the ETT. Due to his dystonia, [R] extends his neck in an unusual position. It is possible that the more rigid tube would "rub" against his trachea (air passage). This could cause erosion of [R]'s trachea (which could be fatal), bleeding and granulomas. In addition, due to his brain injury and mitochondrial disorder, [R]'s dystonia increases when he is uncomfortable. It is very likely that the sensory input from tracheostomy incision site caused by pain at the time of surgery or ongoing inflammation/ irritation which commonly occurs at a tracheotomy site would increase his dystonia. As I've mentioned above, increased dystonia can impair coordination of muscle control including his respiratory muscles and may also increase his secretion production".

17. Dr. B has further considered the possibility that R may survive the extubation for longer than predicted:

"It is not out with the possibility that following extubation, [R] is able to maintain his respiration for longer than a fortnight. Indeed, extubation whilst [R] is optimised provides the best prospect of this. As with all patients at the hospice, if [R] had successfully maintained his respiration for approximately a fortnight, the Trust's palliative care team, in

conjunction with the Trust's PICU team, the Trust's paediatric neurology team, the hospice, [R]'s foster family, his biological parents and children's social care, would review whether it was appropriate for [R] to be discharged from the hospice – and if so, what package of care and support would be required. We have considered whether in those circumstances, it would be appropriate for the ceilings of treatment to be removed. In our experience, we do not think that this would be in [R]'s best interests at that point in time. The ceilings of treatment provide a degree of certainty that enables us to support [R] and his family with a clear plan at the time when, as we anticipate, his respiratory failure worsens. If [R] were able to be discharged from the hospice and remained stable going forwards, my colleagues would work with his foster family, biological parents and children's social care to review whether it was appropriate to amend or remove the ceilings of treatment.”

18. As indicated above (§5) informal second opinions have been obtained from several distinguished consultant paediatric intensivists from other teaching hospitals. Dr. C commented that:

“The team has done everything - maximised medical treatment and even ligated the parotid ducts. I don't think there is anything more which can be offered; it's an unfortunate situation where nothing much can be offered to this poor child”.

Dr. E commented:

“If it is clear that there is no prospect of recovery, and if his condition is clearly deteriorating, then the clinicians would agree that there is no benefit in re-intubation and we should go for an extubation, with a view to an agreement to limit further suffering and intervention.”

19. Dr. I has expressed the following opinion:

“More recently his underlying neurological conditions have impacted on his breathing. Now he is not able to maintain the patency of his airway on his own both because of anatomical reasons and because of excessive secretions. The treating team have looked at possible options to manage these. The Ear, Nose and Throat surgeons felt that the reason for the deterioration in his airway function is multifactorial, not just anatomical, with issues caused by both secretions, the general muscular tone and posture, such that any operation would not materially benefit the boy. The PICU team also have attempted to manage the secretions with medication and ligation of salivary ducts, but this has not helped the patient become able to breathe unassisted.

The team also looked at the option of a tracheostomy, but felt that this intervention would be very likely to exacerbate the neurological issues and problems with his tone, as an indwelling artificial tube in the trachea typically acts as an irritant, and so felt that this was not in his interests.

I have been asked how I and my team at [Hospital] might manage a patient such as this 14-year-old boy. Indeed, children with this sort of problems is not unusual in paediatric intensive care, so we also have experience in managing this sort of problem.

As with all medical interventions, the professionals treating the patient must first ask how their proposed interventions might either prolong good quality life, or might improve the quality of a time limited lifespan. If neither of these are possible, then we must consider whether our best help for the patient is to primarily make their life more comfortable, switching to palliation rather than cure or support as the intentions of our interventions.

In this situation, the boy's life before admission was already potentially difficult to tolerate because of the postural problems and disordered muscle tone. Patients able to verbalise frequently describe joint and back pain, and spasms of pain from the muscles with the abnormal tone. At least in that situation he was able to be at his home and was relatively free of continuous technological support. Now, his condition is considerably worse, with plastic tubing in his airway, the need for frequent suctioning and completely dependent on a machine to enable his ongoing oxygenation. There is no prospect of discharge home or his situation materially changing at any point for the better. In my view, this is an intolerable position for the patient to be in, and if we cannot materially improve his quality of life, he should be allowed to pass away without artificial support.

Reviewing what has been done to date, there are no other reasonable interventions that could be entertained. There is no available treatment for his underlying neurological problems, and the consequent issues that have led to his airway and breathing problems are not amenable to support that would not have worse consequences for his quality of life”.

#### *The (Advance) Emergency Care Plan*

20. The Applicants have prepared and filed an (Advance) Emergency Care Plan which sets a number of ‘ceilings’ for R’s care in relation to his likely respiratory failure. The plan describes the method by which he will be conveyed from the hospital to the hospice where it is agreed that the extubation will be performed. The aim is to perform the

extubation within a short time of his arrival in the hospice once he has settled in. The key passage in the plan reads as follows:

“Priority is for [R] to be comfortable and surrounded by people he knows and loves. Social care will liaise with [R]’s foster and biological parents to determine appropriate attendance. No painful, invasive, or distressing procedures to be undertaken (reintubation, chest compressions, bag valve mask ventilation, deep suction (after removal of the ETT), intravenous cannulation, blood tests) for the purpose of either resuscitation or assessment/treatment of suspected overwhelming infection or other deterioration arising as a result of or related to a progression of his underlying conditions. Pain relief and symptom management medications will be administered as required and detailed in the Symptom Management Plan.”

*The family’s view*

21. It is acknowledged that R’s parents have very considerable difficulty in understanding the implications of this application, or indeed the seriousness of R’s condition. They lack capacity to litigate, and there is reason to believe that they lack capacity to consent to the procedure proposed for their son. The family’s view was conveyed to me through C and U. C told me:

“The doctors ... are very professional, and we have trust in the doctors. Whatever happens will be God’s will”.

U thanked the doctors and carers for R and confirmed that he too was content that God’s will should prevail.

22. The family have made requests for R to be visited in the hospice by a chosen spiritual leader at or about the time of the extubation, and in respect of the funeral arrangements; I am told that these requests will be honoured.

*The foster carers’ view*

23. I enquired at the outset of the hearing whether the foster carers wished to attend the hearing. I was advised that they did not, only because they would find it too upsetting. Their views have been communicated through the written evidence of the social worker and the Guardian. The social worker records their views (taken on 16 August) thus:

“They communicated that they were both in agreement with the hospital’s care plan. They shared a view that they wanted what was best for [R] and were clear that [R] remaining intubated and unable to do many of the things he enjoys is not within his best interest. [The foster mother] advised that she would have preferred for [R] to come home, rather than a hospice, however was not firmly opposed to this if the hospital and courts felt that this was in [R’s] best interests”.



*The guardian's view*

24. I am grateful to Ms Magson for the customarily thoughtful and sensitive approach which she has brought to the case. On appointment, she posed a range of relevant questions for the Applicants, so as to satisfy herself of the necessity/appropriateness of the course proposed in R's best interests. She visited R on the ward on 4 August. She satisfied herself that R is not *Gillick* competent. She observed (via Position Statement filed for this hearing) as follows:

“Due to his severe dystonia, he is largely rigid with an arched back and his day consists of small but persistent interventions. His personal needs are met, he is turned frequently and he has to have his airway suctioned frequently to clear secretions which could cause blockage of his airways. The guardian observed him to be lying on his right-hand side. As he is ventilated, he is surrounded by the necessary machinery which is all in [R's] eye-line.

The Guardian observed staff suctioning [R's] airway. The process of suctioning is uncomfortable and [R] is clearly aware of the procedure, and turned his head away but did not grimace or express distress as far as the guardian observed.

... He has ... lost the ability to actively participate in life. He cannot vocalise due to the ventilation and he has no constant social interaction other than with the foster carer who visits daily. There is no consistent member of staff at the hospital with whom he has been able to form a bond and there is limited stimulation for him as he is very restricted by the ventilator.”

25. The Guardian has not been able to obtain R's own personal views about this application, though one indication is that he appeared to disagree with his mother, when she recently visited, when she told him that she had his permission “to go to paradise”. Ms Magson rightly observes that the weight attached to any wishes and feelings must acknowledge that he is not aware of the consequences of the different options before him. It would also appear that he is not aware of his prognosis, namely that he is likely only to have a relatively short time to live, even if ventilation were continued, and that his condition will become progressively worse over time.
26. The Guardian opines, in conclusion:

“The plan to move to the hospice affords [R] an opportunity to spend the end of his life in a calm environment, where he will not be subject to the constant stream of uncomfortable medical interventions he would have in hospital. He can be with his loved ones and be supported to have a peaceful, dignified death rather than a potentially traumatic death in the PICU where he may find himself alone.”

*The law*

27. R is the subject of a Care Order under *Part IV* of the *Children Act 1989*. It is common ground that although the Local Authority possesses parental responsibility in this way, it cannot rely on *section 33(3) Children Act 1989* to consent to the withdrawal of life sustaining medical treatment: see *YY (Children: Conduct of the Local Authority)* [2021] EWHC 749 (Fam) at [130].
28. I have been referred by counsel to the recently delivered judgments in *Manchester University Hospital Trust v Fixsler* [2021] EWHC 1426 (“*Fixsler*”) and *Re PK (a child) v An NHS Trust* [2021] EWCA Civ 362. In both judgments, extensive citation is made of earlier authorities in this area. I cannot begin to improve on the summary of the law given by Macdonald J in the *Fixsler* case which I reproduce below:

“[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 *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117). 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* [2006] EWHC 507 (Fam)). 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 The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

- 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 and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 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 must 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 *Re A (A Child)* [2016] EWCA 759, 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.

[58] These principles have been reiterated repeatedly at appellate level. In *Re A (A Child)* 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 Hospital NHS Trust v James* [2013] UKSC 67, namely:

"[22] 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

"[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."

[59] In the case of *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ again reiterated 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."

### *Conclusion*

29. Very sadly, R has a poor prognosis whether he remains on ventilation or whether he is extubated. He is currently intubated and requires breathing support from a ventilator; despite the best efforts of the expert clinical team, R has not been able to be extubated successfully even with the support of non-invasive ventilation. R has either been unable to sustain his ventilatory efforts and has then tired and required reintubation or has developed a mucous plug which completely obstructed his airway and required intubation to clear.
30. I am satisfied, on the evidence filed, that there are no realistic options for R to have less invasive ventilation which could be delivered in an alternative setting. Non-invasive ventilation has not been successful in supporting his respiratory function in the past (and would in any event, have a deleterious effect on his quality of life), and his MDT has ruled out a tracheostomy as an appropriate option for him for the reasons set out above. I am satisfied that it is unsustainable for R to remain indefinitely in PICU on a ventilator where his quality of life is so poor and where there is no prospect of improvement. The guardian painted a sorry picture of R's current state, far-removed from the image of a young man with a "full and enjoyable life" about which his carers movingly spoke. There are continued and very real risks of R remaining intubated, including hospital-acquired infection and increased muscle weakness and dystonia, which itself will accelerate his demise. The current treatment offers R no pathway to recovery and his likely lifespan is short. The risks to R in extubation are obvious; indeed, it is almost certain to cause the end of R's life within days or possibly weeks.

31. In considering R's best interests, I have looked at his welfare in the widest sense, not just medical, but social, emotional, and psychological. His best interests are of course my paramount concern, and I make this decision exercising my own independent and objective judgment, albeit greatly assisted by the wealth of medical expertise and experienced which has been marshalled in this case. I have of course started from the strong presumption in favour of taking all steps to preserve R's 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, and I am satisfied that in this case it is outweighed by the pain and suffering, and the other current and likely medical burdens on R, of simply sustaining his breath of life. Tragically, he has no means of recovering from his present state. In my judgement he must now be allowed an opportunity for a peaceful, dignified and calm passing surrounded by those who care most for him.
32. I announced my decision at the conclusion of the hearing on 19 August, and I circulated this judgment the following day. At the hearing, I confirmed that I would be acceding to the application of the Applicants. I was aware that R was to be transferred to the hospice on 24 August 2021.
33. For the avoidance of doubt, I confirm that I have made the following order, without active opposition, namely:
- “It is lawful and in [R's] best interests to be discharged from the Applicant Trust's hospital, transferred to the hospice, to be extubated and for the (Advance) Emergency Care Plan dated 19 August 2021 (as updated or amended in consultation with the Applicant Council and his foster parents) to be implemented with the ceilings of treatment as outlined within it. Provided that care and treatment for symptom management as set out in the Symptom Management Plan dated 19 August 2021 (at Appendix 2 of the (Advance) Emergency Care Plan), and such other treatment and nursing care as is in the judgment of those health and social care professionals providing care to him, clinically appropriate to ensure that [R] suffers the least pain and distress and retains the greatest dignity.”
34. I shall further direct (again without opposition from the parties) that:
- “The Applicant Council is authorised to give consent to any decisions about future care, treatment (including withholding or withdrawing of treatment), discharge or admission that are in-keeping with the spirit of the authorisations contained in this Order and the (Advance) Emergency Care Plan dated 19 August 2021 without further recourse to the court.”
35. That is my judgment.