



Neutral Citation Number: [2020] EWHC 1958 (Fam)

Case No: FD20P00321

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

IN THE MATTER OF THE SENIOR COURTS ACT 1981
IN THE MATTER OF THE INHERENT JURISDICTION
AND IN THE MATTER OF X (A Child)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 21/07/2020

Before:

MS JUSTICE RUSSELL DBE

Between:

**GREAT ORMOND STREET HOSPITAL
FOR CHILDREN NHS FOUNDATION TRUST** **Applicant**

and

MX **1st Respondent**
and

FX **2nd Respondent**
and

X (A Child) **3rd Respondent**
(by her Cafcass guardian)

Claire Watson (instructed by **Hill Dickinson**) for the **Applicant**
Debra Powell QC (instructed by **Bindmans LLP**) for the **1st and 2nd Respondents**
Victoria Butler-Cole QC (instructed by **Cafcass Legal**) for the **3rd Respondent**

Hearing dates: 30th June and 1st July 2020

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

MS JUSTICE RUSSELL

This judgment was delivered in open court. There is a reporting restrictions order in force.

The judge has given leave for this version of the judgment to be published. The anonymity of the child and members of their family must be strictly preserved. 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.

Covid-19 Protocol: This judgment was handed down by the Judge remotely by circulation to the parties' representatives by email and release to Bailii.

The date and time for hand-down is deemed to be 10:00 am on Tuesday 21 July 2020.

Ms Justice Russell DBE:

Introduction

1. Great Ormond Street Hospital (GOSH) for Children NHS Foundation Trust (the Applicant) has made this application for declarations in respect of X, who is the much loved child of her parents the 1st and 2nd Respondents who do not agree to all of the declarations being made. The Applicant Trust is represented before me by counsel Ms Watson, 1st and 2nd Respondents are represented by leading counsel Ms Powell QC, and X is represented by her own leading counsel Ms Butler-Cole QC through her court-appointed guardian. The Applicant Trust seeks declarations that it is lawful and in X's best interests to receive palliative care (also known as symptom management) to keep her comfortable and pain free and to maintain her dignity, and that the following treatment is not in X's best interests and it is not lawful for the following treatment to be provided.
 - a) Endotracheal intubation,
 - b) invasive and non-invasive mechanical ventilation,
 - c) extracorporeal pulmonary support (ECMO),
 - d) inotropic support,
 - e) cardio-pulmonary resuscitation, except to the extent that a reversible cause can be identified for the cardiopulmonary arrest and cardio-pulmonary resuscitation is considered to be clinically appropriate,
 - f) renal replacement therapy,
 - g) elective surgery, except for emergency palliative surgery, and
 - h) re-admission to the paediatric intensive care unit for intensive care treatment, in the event that a discharge from the unit is achieved.
2. Initially X's parents, the 1st and 2nd Respondents, opposed the application and, except for CPR and ECMO, they did not agree that it is in X's best interests for limitations to be placed on the treatment she is to receive in the event of further deterioration in her condition. With the encouragement of the Court two mediation meetings took place on 3rd June 2020 and on 15th June 2020, attended by X's treating clinicians from the Applicant Trust. The meetings allowed for an exchange of information about X's condition and her parents were able to voice their concerns and although no agreement was reached it paved the way for the 1st and 2nd Respondents to read and listen to the evidence of the two independent experts in paediatric intensive care Dr Inwald (instructed by the Applicant) and Dr Nadel (instructed by the 1st and 2nd Respondents) and to agree that it is not in X's best interests to undergo elective surgery, save for urgent palliative surgery.
3. On 30th June 2020, the first day of the final hearing, the 1st and 2nd Respondents told the Court, through their Leading Counsel, that they accepted in light of the medical evidence, they could not oppose a declaration that it is not in X's best interests to undergo endotracheal intubation and invasive ventilation. On 1st July 2020, counsel

for the 1st and 2nd Respondents told the court that they had taken a realistic view of the medical evidence (there was no medical evidence supporting their previously voiced views) on which the Court would be able to base decisions congruent with their wishes, and as a result they no longer opposed declarations that it is not in X's best interests to receive renal replacement therapy or non-invasive ventilation in the form of nasal CPAP or nasal BiPAP. The key remaining issues in respect of declarations were whether it was in X's best interest to receive Optiflow, a form of non-invasive ventilation delivered by cylinder placed under the nose, in the event of a deterioration in her condition; and, whether it is in X's best interests to be re-admitted to the intensive care unit and receive intensive care, including inotropic support (excluding those treatments above), in the event of a deterioration in her condition.

X's medical condition and history

4. X is now 9 years old. One of twins, X was born in the USA in 2010 at 33 weeks' gestation, she was a healthy baby. She is one of the 1st and 2nd Respondents' three children for as well as her twin brother X has a younger brother. When she was still an infant X was diagnosed with Haemolytic Uraemic Syndrome (HUS), a disorder affecting kidney function, and in 2012 developed end stage renal disease for which she received a donor kidney transplant in the USA in 2013; she now has a complex medical history. Her current diagnosis includes renal disease secondary to Haemolytic Uraemic Syndrome (HUS), chronic lung disease and intestinal failure. X underwent the kidney transplant surgery in Boston Children's Hospital in the USA in 2013 and has spent the greatest part of her short life as an inpatient in various hospitals in the USA, Switzerland, and the UK.
5. In fact X has only been well enough to spend 16 days at home during the past seven years and more, a reflection of her need for continuous medical intervention, treatment, and specialist care. In his oral evidence to the Court, X's father, the 2nd Respondent, who was understandably positive and optimistic about his daughter's condition, was at pains to point out that not all of the time that X was in hospital was for her to receive medical treatment *per se* but that she had been in rehabilitation and/or awaiting the provision of appropriate support and care provision at home. Nonetheless the complexity of X's multiple and inter-linked conditions and resulting symptoms have obviously made living at home almost impossible, as submitted by the Applicant X's extensive medical records show that since the beginning of 2019, apart from two days at home, X has been in hospital and overall has spent over a year of her life in paediatric intensive care units. Even though the Applicant supports X's parents' wish to have X at home there remains treatment that she needs which would prevent that happening in the immediate future, matters which I shall return to below.
6. At present X is an inpatient on the Paediatric Intensive Care Unit (PICU) of Great Ormond Street Hospital (GOSH), where she was most recently re-admitted from another ward in GOSH on 12th May 2020 with respiratory difficulties which required invasive ventilation. X's kidney function began to deteriorate and a biopsy of her (transplanted) kidney taken on 15th May 2020 revealed signs of chronic renal failure. It proved possible to wean X from ventilation in late May but her condition rapidly deteriorated and on 29th May the Applicant NHS Trust issued an application to withhold treatment. X's condition suddenly and rapidly deteriorated further on 2nd June 2020 because of her very poor kidney function and fluid accumulating in her lungs and the Applicant made an urgent application to the High Court on the 3rd June

seeking permission to withhold treatment and for declarations that it is lawful and in X's best interests for ceilings to be placed on the treatment to be provided to her and for her to receive palliative care. Her parents, the 1st and 2nd Respondents, did not agree.

7. The proceedings were adjourned to allow for the child to be represented, for the relevant evidence to be filed, and for the child's parents to seek their own medical opinion and reports. On 9th June 2020, the case was set down for final hearing on 17th June 2020 but prior to that hearing the parties requested a further adjournment for mediation to take place and the hearing was re-listed on 24th June. On Sunday 21st June, the Applicant Trust again applied for an emergency declaration out of hours and as the case was due to be heard that Wednesday no order was made by the judge. Regrettably no transcript of the application to the out-of-hours judge was obtained and as the evidence had been from a physician whose evidence was not seen or heard by this court and to which reference may be made, the case had to be adjourned for a transcript of that evidence to be prepared.
8. As a result of the Covid pandemic the case was heard remotely on 30th June and 1st July 2020. The court heard from live witnesses including two of the treating consultants and two consultant intensivists who had given second opinions, and to whom I have already referred namely Dr Inwald for the Applicant Trust and Dr Nadel who had been instructed to prepare a report on behalf of the 1st and 2nd Respondents. I heard from the 2nd Respondent, X's father. There can be nothing but sympathy for X's family and her parents in particular. They are clearly devoted to their daughter and have made every possible effort to ensure that X has had the best medical treatment and care they could secure and have always advocated strongly on her behalf.
9. I have taken some of X's medical history below from the report of Dr Nadel as he was instructed on behalf of the 1st & 2nd Respondents and has given a helpful overview as well as including numerous references to X's history given by her father. As already observed, X was a healthy baby and was well until she was 19 months of age when she developed HUS from which she suffered devastating consequences, including renal failure, gut failure, and severe brain injury. Prior to the kidney transplant in Boston Children's Hospital, X suffered from a cardiac arrest leading to hypoxic ischaemic brain damage, as a consequence of which she developed four limb cerebral palsy with severe dystonia. X has cortical blindness, with no light awareness and severe developmental delay, she is unable to communicate verbally. Secondary to her cardiac arrest, she suffered from ischaemia of her bowel and has had to undergo multiple operations to remove the ischaemic bowel leading to the formation of stomas, episodes of bowel obstruction necessitating further abdominal surgery, gastro-oesophageal reflux, intestinal failure and is dependent on total parenteral nutrition (TPN).
10. X has developed a number of further complications either resulting from the treatment X has required or because of the conditions outlined above; the consequence of the insertion of innumerable indwelling catheters over the years has meant the development of thrombosis of a number of her central veins making venous access extremely difficult. X has developed lymphoedema and has suppressed bone marrow function resulting in anaemia and low platelets. Again this list is not exhaustive.

11. X's family relocated to the UK in December 2015, when she was five years old. During the intervening years, including her two admissions this year, X had five planned routine admissions to GOSH, a transfer there for infection in 2016, and an additional transfer for acute treatment in 2016. When X was first admitted to GOSH in December 2015 she was initially under the care of a Consultant Nephrologist. From December 2015 X had a number of admissions to Epsom General Hospital, St George's Hospital, King's College Hospital, GOSH and the Portland Hospital for management of her dystonia, chronic pain and renal failure in addition to receiving treatment for episodes of pyelonephritis (inflammation of the kidney caused by infection), pancreatitis and chest infections. The recurrent chest infections X has suffered from, as she now has chronic lung disease, have required a number of hospital admissions when she has required admission to the intensive care and episodes of ventilation. Sadly, this list is not exhaustive.
12. X's more recent history leading to the current situation as summarized by X's father and as set out in Dr Nadel's report is that X was admitted to GOSH while already in King's College Hospital on 2nd February 2020 and discharged back to King's on 21st February 2020. The discharge summary from GOSH included the information that X *"was meant to have an Operation for the hiatus hernia [or fundoplication]. Unfortunately, she developed a chest infection on 9/2/20 and her surgery [for 10 February 2020] had to be postponed. She is being transferred back to [King's] and will come back to us closer to the op date"*. The surgery which was arranged to take place on 16th March 2020 did not take place.
13. In March, during her admission to King's College Hospital, X suffered a complication from a venous line that led to swelling of her right shoulder and arm. This wound or injury remains problematic and unresolved. According to her father the surgery could not be performed at King's and pending confirmation of a new date there were discussions about X returning home in the meantime, but she could not do so as overnight on 19th/20th March 2020 X had developed a chest infection caused by aspiration pneumonia, which her parents were told was caused by reflux caused by the untreated hiatus hernia. It is of note that prior to the February admission this year X had suffered from three chest infections over the past two years. X was readmitted to GOSH on 23rd March 2020 from Kings which the court was told was because of reorganisation of medical staff to release them to deal with the Covid pandemic.
14. X has spent most of the past three plus months on intensive care. Between 23rd March and 30th April 2020 X was an inpatient on PICU at GOSH, where she was reviewed by the vascular team. Following discharge from PICU (to another ward; at GOSH all wards are considered by the hospital to be high dependency) her right arm and shoulder did not improve and on 11th May 2020 the wound was explored under anaesthetic. Overnight X's need for oxygen increased and she was re-admitted to PICU on 12th May 2020 where she was sedated, intubated, and ventilated. It was during this current admission that X's kidney function began to deteriorate and she was producing less urine. An ultrasound scan revealed that the appearance of the kidney was abnormal and a subsequent biopsy of the kidney revealed signs of chronic renal failure described as 30-40% irreversible cortical change. On 28th May 2020 X's kidney function was said to be at no more than 17% capacity.
15. As a result of that deterioration excess fluid had accumulated in X's body, including in her lungs leading to respiratory difficulties. The worsening renal function and

respiratory compromise was treated with medication and invasive ventilation under sedation. X was weaned off the ventilator and was able to breathe for herself on room air by the morning of 1st June 2020, but her respiratory function rapidly deteriorated again in the early hours of 2nd June 2020 and she needed non-invasive ventilation. A chest x-ray taken on 2nd June revealed significant pulmonary oedema and her blood creatinine levels had increased to over 400umol/L, from a base line of 60-80umol/L prior to her admission, which was indicative of significant deterioration in renal functioning. As a result of the breathing difficulties secondary to the pulmonary oedema X was reintubated and was in receipt of invasive ventilation on the PICU.

16. X's kidney function improved but the Court was told by the Applicant Trust that while the clinical team continued to attempt medical management of X's renal failure, but it was their view then, and is now, that it is not considered to be technically possible to treat X's end stage renal failure with haemodialysis or peritoneal dialysis and the multi-disciplinary treating team at GOSH did not, and do not, consider that it is in her best interests to attempt to insert a peripheral line to provide temporary haemofiltration. During her current admission X's case and her treatment have been the subject of a number of multidisciplinary team meetings. The consensus was, and remains, that any escalation of treatment, including, but not limited to, renal replacement therapy, extra corporeal pulmonary support, cardio-pulmonary resuscitation, or increased levels of intensive care support, are not in X's best interests. The clinical team at GOSH considers that escalating treatment carries significant burdens and would have minimal benefit for X. It is the strongly held view of the clinical team that it would not be in X's best interests to have an unplanned death on PICU and that she should receive palliative care to allow her to have a compassionate and dignified death surrounded by her family at home if possible or elsewhere if not.
17. It has been submitted by the Applicant that this most recent intensive care admission should be viewed as part of an evolving and highly complex picture, and on any objective view that is the case. X's parents, entirely understandably, chose to focus on any improvements in X's condition following her acute deteriorations during this admission but those improvements are relative as there has been no sustained or substantial improvement in X's pathology. The medical evidence is (as can be seen above) that X's admissions to intensive care have become more frequent and longer in duration. Moreover the records and medical opinion disclose that an improvement in one condition following an acute deterioration inevitably has a negative impact elsewhere, such as restricting fluid intake to prevent fluid overload and retention affecting the child's chronic kidney disease and her nutrition, or that any and each deterioration requiring invasive ventilatory support causes further damage to X's already damaged lungs. As Dr Nadel put it in his report, "*she has recurrent acute crises from which she recovers and then soon deteriorates again either on the PICU or on the ward where she only managed a few days. The periods in which she interacts with her family, enjoys music and giggles/smiles are very infrequent and I understand that she has spent only about 16 days in her home environment in 7 years. The issue for the PICU team is the balance between these few episodes (where she is able to interact with her family) and the far more frequent periods she is being instrumented and subjected to painful procedures.*"

18. As to the prognosis for X the opinion of all the treating physicians and multi-disciplinary team at the Applicant hospital and the independent medical experts including Dr Conway (instructed on behalf of X's parents) is that X is reaching the end of her life although, quite rightly, none would proffer a definitive time-scale for X's death, and that it is in her best interests to be provided with a good quality palliative care package. While Dr Nadel told me that experience had taught him to be wary of predicting when death might occur and did not do so in respect of X he supported the view that it would be appropriate to institute a palliative care plan for X.
19. In respect of X's quality of life, I accept that evidence comes best from the 1st and 2nd Respondents, and, in particular, from the evidence of X's father the 2nd Respondent whose oral evidence I heard. I shall return to it in some detail below.
20. The Applicant's position is that the treating team want to achieve the same outcome for her as her family and to maximise X's opportunities to enjoy positive interaction and experience life with her family in the least medicalised environment possible, to keep her comfortable and pain free and to maintain her dignity. They are clear that providing Optiflow treatment or readmitting X to the intensive care unit would not achieve or help to achieve that shared aim. X's parents do not agree with that latter stance, nor does her guardian.
21. Referral to Ethics Committee. During her latest admission to PICU X's case was referred to and discussed by the Applicant Trust Ethics Committee on 15th May 2020, where the consensus reached was that further invasive treatments, including renal replacement therapy, were not in X's best interests and that the focus should be on palliative care to maximise her comfort and quality of life prior to death. Although no external second opinions were sought this process, regrettably it did not involve the 1st and 2nd Respondents. I was told that there is no protocol or definitive guidance for the constitution and conduct of Ethics Committees, particularly as to the involvement of patients or their families in the meetings and decisions. Counsel for the child (through her guardian) drew my attention to the UK Clinical Ethics Network which on its website notes that "*Current practice of most UK CECs does not usually involve patients or their families and carers in the committee's discussion but some committees have considered cases at the request of a patient's family or carer.*"¹ In addition I was referred to an article, Newson, Ainsley J. "The role of patients in clinical ethics support: a snapshot of practices and attitudes in the United Kingdom." *Clinical Ethics* 4.3 (2009): 139-145, which I have read.
22. I consider that a lack of involvement by patients and/or their families is itself an issue of medical ethics and I am most surprised that there is not guidance in place to ensure their involvement and/or participation. While it is a matter of common sense and good practice for medical professionals and members of a multidisciplinary treating team to have discussions *sans* the patient or their relatives to enable an uninhibited and frank exchange of professional views and information without the need for the empathic, sensitive and supportive language used when speaking to patients and/or their families, the absence of any prior consultation or participation, cannot be good practice and should generally be unacceptable. Even at hastily assembled meetings there should be notice taken of the views of the patient and/or close relatives which could take the form of some written notes or letter submitted on their behalf. There

¹http://www.ukcen.net/education_resources/support_guide/section_a_clinical_ethics_support

should be guidance on patient/family participation and a clear protocol of how and when they are informed as to the arrangements being put in place for an Ethics Committee to meet along with being informed as to the outcome.

23. As observed by X's guardian in situations such as X's, where the quality of life of a disabled child with complex medical needs is a central issue, the involvement of parents in the clinical ethics committee process is essential. The Guardian may have been reassured, as I was to a degree, to be informed that the Applicant generally takes the approach of involving parents, but the fact that in this case, which was then the subject of proceedings in the Family Division and where there already were (and remained) issues between the parents and the hospital there was no involvement of the parents, or of their views being placed by the committee for consideration during their deliberations, is a matter of some concern. I remain uncertain as to why it was not felt possible to involve the parents with the Ethics Committee in this case, particularly as matters progressed and the urgency and nature of the decisions in issue changed, so that there was time for further advice and opinion from the clinical ethics committee to be obtained. The fact that outcome of the meeting was discussed with the parent's later that day and after the meeting does not cure the deficiencies set out above and had the effect of both raising their anxiety and contributing to their feelings of alienation and exclusion.
24. Second Opinions. As we have seen the Applicant sought a second opinion from Dr Inwald, a consultant Paediatric Intensivist. X's parents wished to obtain their own second opinions and they have been able to file evidence from Dr Conway a retired Consultant Paediatrician with a special interest in paediatric infectious disease, immunology, and respiratory medicine, Dr Jan Dudley, consultant paediatric nephrologist at the Bristol Royal Hospital for Children and from St Mary's, London, a consultant paediatric intensivist, Dr Simon Nadel. I have heard oral evidence from Dr Nadel as well as from the intensivist, Dr Inwald, instructed by the Applicant to both of whom I have already made reference.

Law

25. There is no dispute as to the law: the decision is one of best interests. The court is being asked by the applicant to make an order that certain treatment is to be withheld. In principle it is the responsibility of parents to make decisions on behalf of their child, including any consent to medical treatment or, as in this case agreeing for some treatment to be withheld. When, as here, parents do not agree with the proposed treatment or withdrawal of treatment proposed by the clinicians responsible for their child's care, the court can intervene and overrule their refusal even if it could not be said to be unreasonable (*Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242; guidance as to how the court should exercise that authority was set down by the Court of Appeal in *Wyatt v Portsmouth NHS Trust* [2005] EWCA Civ 1181 [87]; "*In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount and the judge must look at the question from the assumed point of view of the patient (Re J). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrefutable (Re J) The term best interests encompasses medical, emotional and all other welfare issues (Re A). The court must conduct a balancing exercise in which all the relevant*

factors are weighed (Re J) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A)”

26. The law is well established and there is no need for extensive reference to authority and case law, particularly as there is no dispute in respect of the legal framework pertaining to this case, but it is worth repeating the words of McFarlane LJ (as he then was) in *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, “*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.*”
27. The limited dispute which now remains between the Applicant and the 1st and 2nd Respondent parents falls to be considered under the Inherent Jurisdiction of the High Court pursuant to the Senior Courts Act 1981 s19, this jurisdiction can only be exercised in this case because X, as a child, lacks the capacity to make a decision for herself. The decision as to what is in X’s best interests is to be taken by applying an objective test in order to determine what are the best interests of X. In considering her best interests, I shall include her medical, emotional, sensory perceptions (these in turn include her ability to give and receive love and affection, her pleasure, enjoyment of her surroundings, and her pain and suffering) and the human instinct to survive and prolong life.
28. There is a strong presumption to be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be so in the patient be they child or incapacitous adult, nonetheless as expressed by Lord Donaldson of Lynton in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33, the presumption is not absolute for, as he said; “*We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.*”
29. My decision has wholly to be based on the specific facts of X’s individual case. The views and opinions of the treating clinicians and medical professionals and the parents must be carefully taken into consideration. X’s parents have spent a great deal of time with their child throughout her life, their views have particular value because they know X better than anyone but to consider her situation objectively I must keep in mind that the view of any parent is understandably likely to be coloured by their own emotions, feelings and beliefs. The wishes of a parent provide information and an explanatory background as to the quality of the child’s relationship with her parents but it is not necessarily an objective view of the best interests of the child.
30. There are limitations of the court’s powers as applied by MacDonald J in *Re Y (No 1)* [2015] EWHC1920 (Fam) at [34] of his judgment “*It is important to note that the court has no power to require doctors to carry out a medical procedure against their own professional judgment.*” Later he said [37], “*Whilst the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment that obligation does not extend to providing such*

treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned (see R (Burke v The General Medical Council [2005] EWCA 1003)."

31. In the case of *Re A (A Child)* [2016] EWCA Civ 759, the Court of Appeal confirmed while the application of the law in this area requires great sensitivity and care it is best summed up in two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC67, [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.*" At [39] she continued; "*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.*"

Applicant's case

32. There are two issues that remain to be decided, that of the provision of Optiflow ventilation and the re-admission to an intensive care ward or unit. X's parents have taken advice and read and accepted that the preponderance of the medical evidence, including that of experts instructed on their behalf, is that there should be ceilings of care. In this they are to be commended. The Applicant seeks a declaration that it is not in X's best interests to receive short-term treatment with Optiflow. The Applicant recognises that there was the support for at least a trial of short-term Optiflow from Dr Inwald and Dr Nadel and submits that when their and the medical evidence is analysed "*neither expert considers that Optiflow treatment is likely to be effective in [X]'s case and both experts acknowledge that there is a real risk that she will die in hospital attached to an Optiflow machine.*" This does not concur with my scrutiny of their evidence.
33. The Applicant places reliance on the evidence of the lead treating consultant who gave oral evidence for most of the first day of the hearing and that physician's opinion, which was largely unchallenged by expert witnesses, that there was "*downwards trajectory*" for X who was stuck in "*a cycle which if I am to be honest I think she is dying and all we are doing is propping up and she gets another problem and then becomes unwell.*" It is the firmly held view of the body of consultant paediatric intensivists at the hospital that X should be provided with palliative care to make her death as comfortable and pain free as possible and any intervention, of which Optiflow was one, was considered to be contrary to her best interests.

34. It was accepted that Optiflow is not invasive ventilation, nonetheless, the leading treating consultant was of the view that it was still unpleasant as there is a continuous flow of oxygen being blown through a nasal cannula which would be fixed to X's upper lip below her nose which would blow air into her nose at high pressure which is upsetting. The doctor went on to say that it is an intervention that would require X to be in hospital, rather than at home with her family and may require sedation if it causes discomfort. This evidence would have considerably more force if it was clear that Optiflow (rather than any one or more of the myriad conditions and symptoms X suffers from) caused pain or distress and that there was a real likelihood of X returning home in the near future but it is clear, based on this same witness's testimony, that the need for X's TPN (sole form of nourishment) to be titrated with her other medication and the unhealed wound on her right arm and shoulder make a return home difficult if not impossible at present.
35. Equally the submission that ventilatory support using Optiflow would not produce any benefit for X in the initial stages of an acute deterioration is far from clear on the evidence before the court notwithstanding the evidence of the lead consultant and her understandable worry and concern that X should not "*die on the machine. I really don't want that to happen.*" In cross-examination the lead consultant said that while X had been agitated, distressed and in pain while on Optiflow it was not possible to be certain that the Optiflow itself was the cause of her distress, it was a potential cause as when taken off Optiflow, X was noted to be much more settled and comfortable. It coincided with further pain relief and the evidence, taken as a whole does not support a conclusion, on the balance of probabilities, that Optiflow was the major, still less the only, cause of distress.
36. It is the Applicant's case that, as accepted by both Dr Inwald and Dr Nadel on their review of her medical records, any future deterioration for X is likely to be sudden and rapid, and that intensive care treatment has no role in end of life care. Contrary to the Applicant's case the evidence of Drs Inwald and Nadel was supportive of Optiflow being provided if of benefit to X, but that it would not be in her best interests if X presented in severe respiratory distress or respiratory arrest; or if X was considered to be actually dying and it was the view of the clinicians at the bedside that Optiflow would be of no benefit; or if X was showing signs of distress or discomfort on Optiflow.
37. While Dr Nadel accepted that it was not likely that Optiflow would be of benefit, based on X's recent history it was still possible and, unless she was actively dying "*it might be beneficial.*"
38. I do not accept that the evidence of Dr Inwald or Dr Nadel was that there was a real risk that X would die in hospital on Optiflow. In the first place there are two different issues, dying in hospital, which given X's history and current condition is not unlikely and, secondly, that she would die while receiving ventilation by Optiflow. I find it inconceivable that if she were actually dying any of the treating clinicians would countenance her remaining on that machine. If the court considers that it may be in X's best interests to receive Optiflow if of benefit to her as described by Dr Nadel, then the Applicant seeks for its provision to be time limited to no more than one week.

39. The Applicant submits that there is no support in the evidence for X to be re-admitted to an intensive care unit or for her to receive further intensive care, including inotropic support in the event of a deterioration in her condition. I accept that Dr Nadel's clear evidence when questioned by Ms Powell QC was that he would not support the giving of inotropes in any circumstances. Dr Nadel supported the view that there should be parallel planning for palliative care and that most children on a palliative care pathway should not come back to intensive care and should not be subjected to burdensome, painful or distressing procedures nor actively managed to treat organ failure.

1st and 2nd Respondents' position

40. The 1st and 2nd Respondents accept that the Court is required to make a separate decision in respect of two treatments Optiflow, and re-admission to PICU. It is axiomatic that the fact that some treatments are no longer in issue in the proceedings, notwithstanding the fact the withholding of them may result in X's death, should not be determinative in respect of those treatments that remain to be considered. The evidence of the lead treating physician (on PICU) was that she and her consultant colleagues at the Applicant Trust considered that it was in X's best interest not to receive further invasive and often painful treatment and that she should be allowed to die. On behalf of her parents it is submitted that that is the wrong approach to this case as it is not a case about withdrawal of life sustaining treatment; for example, of withdrawing X's source of nutrition TPN and allowing her to die. Moreover it is X's parents' case that because the treating clinicians consider X has had too many invasive interventions already they do not think she should have any more. In any event, whatever the possible difference of clinical opinion between current treating clinicians and those who have previously treated X, the interventions now in question are not very burdensome. I accept the latter submission.
41. I do not accept that the Applicant's submissions that there has been no sustained or material improvement in X's underlying condition is irrelevant. The succinct manner in which Dr Nadel described the dilemma faced by those treating X alluded to above, as a child who faced acute crises from which she recovers and then soon deteriorates again and that the periods in which she interacts with her family and apparently enjoys life are very infrequent ... the issue for the treating team is the balance between these few episodes and the far more frequent periods she is being instrumented and subjected to painful procedures, commends itself as an encapsulation of the question from a clinical perspective.
42. Optiflow. The 1st and 2nd Respondents submit that the independent medical evidence of Dr Inwald who said in his second email of 30th June 2020 "*[Optiflow is] a gentle treatment which ... is generally comfortable and well tolerated in children. My view is that would not (sic) be an excessive burden for her to have this form of treatment*" should be accepted. Further in his evidence he said that he thought Optiflow is much better tolerated than nasal and face mask ventilation and while he understood the Applicant's reluctance to accept it could be used, it was in his experience quite well tolerated and he thought that the balance of benefit and burden in regard to Optiflow is at a level where one might consider using it as a step up form of treatment if trying to bridge X to recovery from a mild chest infection. It should not interfere with other forms of palliative care and X could be continued on morphine infusion and kept

comfortable, it could be stopped if it proved otherwise and is not an excessively burdensome treatment.

43. In his evidence on behalf of the trust Dr P (another treating consultant on PICU) agreed that, to the best of his knowledge, the Optiflow had been well tolerated by X, but that when she has Optiflow and CPAP X had a distended abdomen and it was feasible that the Optiflow contributed to the accumulation of gas in her stomach. Dr Nadel considered it was much more likely that the effects observed, if they had occurred, would have been caused by CPAP. Dr Nadel did not agree with the suggestion put to him in cross-examination that Optiflow leads to an increase in secretions and consequent increase in suctioning. X's father told the Court that X had had Optiflow on several previous occasions and that he had never been made aware of any clinical view that she was distressed by it.
44. The 2nd Respondent's evidence was that Optiflow could be a benefit to X if it were provided for some simply reversible cause of respiratory distress such as extra secretions that had not been cleared. This evidence was supported by Dr Nadel who also said that if there was respiratory distress because of an intercurrent viral infection, it could provide a benefit to X. In the transcript of the out of hours hearing on Sunday 21st June 2020, when X was deteriorating because of a suspected chest infection Dr S had said in cross-examination that the prescribed antibiotics may be the correct ones and may reverse the chest infection. He went on to say that respiratory support may plateau at the Optiflow that X was on and that X *"has been in this situation before. She's had recurrent episodes of respiratory failure and she's been treated with Optiflow and got better so that is possible, that is a possible outcome."*
45. Although Dr Nadel had not identified evidence that X had benefitted in the past from short-term Optiflow (meaning less than a week). He said that it was sometimes hard to identify benefit when reading from records or observations, as sometimes it was a clinical impression rather than something very objective. Dr Nadel had reviewed X's extensive medical records of over 10,000 pages from which Optiflow was not identified as a significant issue in her case: he had concluded the use of Optiflow might be beneficial. On behalf of the 1st and 2nd Respondents it is submitted that it is not possible to say because a short period of Optiflow was not helpful in this acute episode, that it could never be helpful and pointed to Dr S's evidence.
46. Dr Nadel agreed with me in his oral evidence that he would not wish to deny X any possible benefit of the short-term use of Optiflow as part of her package of care. He told me that if it could be used to either alleviate her symptoms, *"or get her over a minor bump in her road (which has been very bumpy up to now) in the short term, to see if it provides any improvement, and if it doesn't clearly it can be removed and further symptom relief can be put in place. If it alleviates respiratory distress, if it buys some time to see what the trajectory of [X]'s progress is, then it may be useful. I mean symptom relief or palliative care is not necessarily a direct route to death, the whole point is symptom relief to make life more comfortable although I am not an expert, I think the whole aim to make life more comfortable and a decision has to be made at some point whether this is the final pathway to death and I think that the point of the Optiflow wasn't as part of a symptom relief or palliative care plan it was to determine whether this a rapidly reversible deterioration that would allow her to go back to her baseline and if not it would become clear very quickly and if it was she*

would revert to her baseline.” Dr Nadel said that although there was always the possibility that once she was on Optiflow it might be difficult to wean her off it, that would allow further discussion about symptom relief to occur. There is, in fact, no evidence that X has had difficulty being weaned off Optiflow.

47. On the evidence they gave before me both Dr Inwald and Dr Nadel considered that the provision of Optiflow would be in X’s best interests in certain circumstances. Neither Dr Inwald nor Dr Nadel gave evidence of a significant risk of X dying while on Optiflow. The import of their evidence was that should she deteriorate on Optiflow, it could and would be stopped and she would be made comfortable.
48. Readmission to Intensive Care Unit. Entirely understandably X’s parents want their daughter to survive and be with them for as long as possible. They accept that she will die sooner rather than later but say that how soon cannot be predicted accurately; indeed, there is not any dispute about the fact that X’s death cannot be predicted with real precision. The Applicant has not identified significant burdens associated with X being re-admitted to PICU but relies substantially on the assertion or assumption of the treating clinicians that re-admission to PICU is inconsistent with a palliative care plan or symptom management. I was told that Optiflow cannot be provided on wards other than PICU as not all the staff are trained in its use. The Applicant has sought to rely on the burdens of being on an intensive care unit *per se* but there is no evidence that X is particularly disturbed by the environment of PICU as her repeated experiences of being in intensive care have made her familiar with that medical milieu. As her father said X’s blindness means she has no appreciation of light and dark so that her sleep pattern would not be unduly disturbed by being on PICU. Dr Inwald’s evidence was that to re-admit X to PICU to receive Optiflow by itself would not be unduly burdensome.
49. The expert medical evidence was that there should be parallel planning in the form of palliative care, or of symptom control as the treating physicians at GOSH prefer. The unchallenged evidence of Dr Inwald and Dr Nadel was that palliative care plans are individual to each child, which, it is argued on behalf of X’s parents and does not necessarily preclude the provision of Optiflow or admission to PICU were it to be consistent with that plan. The 1st and 2nd Respondents are understandably concerned that should the circumstances require care or treatment or symptom control that could not be given on the ward, which are not precluded by the specific terms of the declarations, such care, treatment, or symptom control should not be excluded if it is in X’s best interests to be re-admitted to PICU to receive it and ask that the application for a declaration that X should not be re-admitted to PICU should be dismissed.
50. When Dr Inwald was instructed to consider all ceilings of treatment originally sought by the Applicant in his first report which included whether it was in X’s best interests to continue to receive intensive care treatment, he said that the decision was “*difficult and subjective and to a large extent depends on the observer’s opinion of quality of life and a decision that this would be an unreasonable burden to the child.*” It was submitted by the 1st and 2nd Respondents if the decisions as to further intubation and ventilation, renal replacement therapy, elective surgery were correctly to be described as “delicate”, “nuanced” and “difficult and subjective” then the decisions regarding Optiflow and re-admission to PICU are even more so as the associated burdens are much less onerous and unreasonable than those of the more invasive treatments that

have been ruled out; and that, as set out in *Re T (A Minor)(Wardship: Medical Treatment)*, [1997] 1 All ER 906, p917, “*in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature.*” In *Aintree*, the treatments in question were very burdensome. It is submitted on behalf of X’s parents that the evidence in X’s case does not support a finding that either Optiflow or readmission to PICU would be “*very burdensome*”. Indeed, the weight of the evidence in respect of this particular child, is that they are not. The 1st and 2nd Respondents submit that Optiflow should be excluded from any declaration that it is not in X’s best interests to receive mechanical ventilation.

The Child’s case (by her guardian

51. On behalf of X her guardian and legal representatives have made written submissions having heard the oral evidence and considered the other parties’ closing submissions. The guardian, on X’s behalf, supports the making of a declaration that it is lawful and in X’s best interests to receive palliative care/symptom management; and that the additional wording proposed by the Applicant is neither appropriate nor necessary, in the guardian’s view, as it imports subjective concepts and the goals of treatment into a declaration which should be limited to identifying what treatment can lawfully be provided. I agree.
52. On the basis that the guardian accepts the unanimous medical evidence that the burdens of these treatments would outweigh any potential benefit to X, since the prospects of successfully treating any underlying pathology that has caused a further deterioration in her condition are very small and the treatments themselves uncomfortable or even painful, the guardian on behalf of the child, supports declarations being made that the following treatments are not in X’s best interests and it is not lawful for such treatment to be provided:
 - i) Endotracheal intubation,
 - ii) Extracorporeal pulmonary support (ECMO),
 - iii) Inotropic support,
 - iv) Cardio-pulmonary resuscitation, save to the extent that a reversible cause can be identified for the cardiopulmonary arrest and cardio-pulmonary resuscitation is considered to be clinically appropriate,
 - v) Renal replacement therapy,
 - vi) Elective surgery except for emergency palliative surgery.
53. And, for the same reasons, a declaration that the following treatment is not in X’s best interests and it is not lawful for treatment to be provided:
 - i) invasive and non-invasive mechanical ventilation (see below regarding Optiflow).
54. The guardian accepts the unanimous medical evidence that the pain and discomfort caused by these treatments outweighs potential benefits in circumstances where X is

unlikely to recover a quality of life she and her parents would find acceptable, and there is no realistic prospect of curing the underlying conditions which are inevitably going to lead to her death, probably within months.

55. On the child's behalf the Guardian does not support the making of a declaration that non-invasive ventilation, specifically Optiflow/HFNC, is not in X's best interests. The guardian invited the court to accept the evidence of Drs Inwald and Nadel that Optiflow is a gentle treatment that is generally well tolerated by children, that if problems arise with its use these will be identified and the treatment stopped and that the provision of oxygen in this way may mean that X feels more comfortable if her breathing is difficult, and may be supported to recover from a temporary deterioration in her condition. I agree with the observations made by the guardian that Dr Inwald and Dr Nadel gave a realistic and objective account of the benefits and uses of Optiflow, and that the evidence of the leading consultant and the Applicant's witnesses has been affected by their strong view that no further treatment of any sort (beyond symptom management) should be given to X and their assertion that practical arrangements in GOSH mean that Optiflow is a treatment that is only given within PICU. I have since been told that X has in fact received Optiflow ventilation on another ward on her discharge from PICU.
56. As her guardian submits it is difficult to predict the inevitable progress of X's deterioration although there may be short periods when she is relatively well, stable, and able to interact with her parents and family as she has done in the past. In keeping with the evidence of Dr Nadel, it is submitted on X's behalf that if circumstances arose in which the provision of Optiflow was available it may be that it would make X feel more comfortable and provide a 'bridge' (to use Dr Nadel's word) through a period of mild infection. While none of the clinicians whose evidence is before the court thought it likely, as can be seen from the relative recovery that X made during the currency of these short proceedings it remains a possibility, and it would be wrong to make a blanket declaration that the use of Optiflow would never be in X's best interests. X's guardian has submitted to the court that she is mindful that for X, as other children with serious illnesses, it is difficult to predict the fluctuations in her presentation and the further problems that may arise, which makes it risky to rule out treatments in advance which may be of benefit and do not, in themselves, pose a significant burden. In that submission the guardian, on X's behalf, is supported by the evidence of Dr Nadel.
57. At this point it is pertinent to record that I found the evidence of both Dr Inwald and Dr Nadel helpful. Both had prepared comprehensive and thorough reports and gave measured and carefully considered evidence. They are independent witnesses and I accept their evidence in respect of the relatively benign nature of the mechanics involved in any child receiving ventilation by Optiflow. Moreover I accept the submission made on behalf of the child that the 2nd Respondent's evidence in respect of X having received respiratory assistance by way of Optiflow on numerous occasions in the past without discomfort, is evidence that can be relied on. On behalf of the child the declaration proposed on behalf of the parents set out in their closing submissions is supported and the court is asked to make a declaration in those terms.
58. Like her guardian and legal representatives I am concerned that insufficient notice has been taken of the family's evidence by the Applicant Trust, the Applicant's solicitor initially left X's father's statements out of the Court bundle and her family's evidence

about X and her previous quality of life (as contained in the 2nd Respondent's statements) could not have formed part of the clinical ethics committee consideration as it did not have such information made available to it. From the point of view of the child's guardian there appeared to have been an assumption made by the Applicant that the duration of her hospital stays necessarily meant that her quality of life had been poor. X's parents have found communicating with the Applicant and the treating physicians at GOSH difficult; and the treating team in their turn have complained about their interaction with the 1st and 2nd Respondents.

59. I am not going to adjudicate on where the fault lies for this situation, the Court had to insist that mediation was imperative, both to assist in narrowing the issues to be decided, and to reduce the levels of distress for this family. There has been occasion when the Court was misinformed by the Applicant's solicitor about the 1st and 2nd Respondent's stance on issues of treatment. After the hearing the Applicant's solicitor informed the court by email that X's parents were reopening a ceiling of treatment in respect of X's kidney conceded at trial, to be corrected by those representing the child's parents. It would seem that the Applicant's position has been informed by an understandable reluctance on behalf of the treating team to inflict burdensome and painful treatment on a child who, in their opinion, has already had too much intervention. On the other hand X's parents have seen X's illnesses as something that they must overcome on her behalf, an approach for which they cannot be faulted, and the result in this case is of the two parties approaching the child's current situation and her overall deterioration as if from opposing sides during any consultation or discussions of X's case which took place. It is highly regrettable that it is not possible to discern from the evidence before the court any real consideration of the benefits to X and the positives of quality of her life on the part of the Applicant.
60. The declaration sought by the Applicant that there should not be treatment in the form of "*Re-admission to the paediatric intensive care unit for intensive care treatment, in the event that a discharge from the unit is achieved*" is not supported by the guardian. On behalf of the child it is submitted that a declaration of this sort is not helpful, as the crucial component of the declaration 'intensive care treatment' is not defined and that the preceding declarations had specified particular treatments which are or are not in Helene's best interests. Many of them are treatments that would likely fall within 'intensive care treatment' and so have already been addressed. As observed on behalf of X, and I agree, if any treatments being offered by treating clinicians and considered to be in X's best interests could only be provided in PICU then a decision would need to be taken at the time whether an admission was appropriate.
61. The burdens associated with admission to PICU would properly be one factor in such a decision, but it is unlikely to be determinative, nor should it be given more weight than other more substantial burdens and/or benefits. As Baroness Hale observed in *Aintree*, the first instance judge Peter Jackson J (as he then was) was right to be cautious about making declarations in circumstances that were fluctuating and uncertain. This is surely so in respect of X who has a myriad of interlinked conditions which fluctuate. The frank evidence of Dr Nadel was that his experience as an intensivist had taught him that it is not possible to predict with accuracy the rate at which a terminally ill child would deteriorate and that there would be fluctuations in presentation leading up to death. His opinion was not based on an unwillingness to predict her death, as submitted by the Applicant, but on his years of experience. Even

during these proceedings which lasted just six weeks X has deteriorated at times, and at times improved.

X's Best Interests

62. Benefits. In considering X's best interests I shall start by looking at the positives in her life. Her parents love their daughter very much and the 2nd Respondent has described her interaction with them, with her twin brother and, to a lesser extent her younger brother (as he does not go to the hospital as often). It is her parents who know X best and are best able to assess her quality of life, they also accept that *"X's lifespan will without doubt be limited. It is also correct to say that there may well come a point where the burdens of further care outweigh the benefits. For example, when we were told, as we initially were, that dialysis was simply impossible, we reached an agreement with [the doctor] that resuscitation beyond reversing simply reversible causes would not be undertaken."*
63. The 2nd Respondent endeavoured to describe X's quality of life and the benefits of living to her. Although he said it was *"a difficult thing to explain"* it is my view that he was well able to impart X's world, albeit a world with considerable limitations because of her multiple disabilities. I accept entirely that X's place in her family and in her world is not *"an abstract concept"* either to X herself or to her family, or indeed to those who have taken or had the time to learn how to communicate with her. The 2nd Respondent said that it is important to remember that X had a period of time in her infancy when she did not suffer from developmental delay and had full sight. X is still able to hear and is able to interact with her family, with professionals, the nurses, physiotherapists, and teachers, with whom she has developed a relationship, she loves music and has an eagerness to learn.
64. While X cannot speak she can vocalise and communicate by different inflexions in her voice and expressions on her face which, her father says, convey very well what she is thinking and feeling to those who understand. X continues to point when she wants something and is sensitive to the tone of people's voices and astute to what is happening so that her family never say goodbye as that makes her frown but say *"see you later"* in a cheerful way. Her father describes her world, populated by those she likes, and made up of things that are fun and give her pleasure. She likes being read to and knows that it is the beginning of a story *"when we clap the book together...when we knock on a book, she knows that it is the end."* X is particular in her likes and dislikes, and *"when offered a choice of five or six lip balms to smell, she will give the biggest smile to indicate the one she wants. She also hates the noise of the television, but loves music, different music for different moods. Her personality has allowed her to be capable of so many things written off as impossible or out of reach. By way of one example, at one point, she knew 15 sign language letters; by way of another, in 2018, our friend Ali taught her to say 'Ali'."*
65. Her ability to hear and interact has also allowed nurses to develop a way to communicate with X. *"A nurse with a beard will always say to her 'tickle, tickle, crickle, crickle', which causes her to squeal. Another will play her a song about a turtle swallowing a bar of soap in the bathtub: she has only to hear the first three notes of the song before she squeals with glee. Her giggles can go on and on. She knows that 'vroom, vroom' means a trip out in her wheelchair."* The 2nd Respondent refers to X's hospital notes from Kings of a few months ago, in December 2019, and

January and February 2020, which record for example X as being “settled”, “smiling” and “laughing” when interacting with others, and as having demonstrably “enjoyed” her physiotherapy and teaching sessions.

66. The 2nd Respondent says the “cheeky part” of X’s personality remains and in his evidence gives as an example of how X can hear the sound of a nurse’s badge knocking against the plastic of her bed which she will swipe off to startle the nurse, and on succeeding, X “will give the biggest belly laugh. The nurse ‘telling her off’ will only cause her to laugh harder.” X can, he says, demonstrate when she is not keen on an individual, she will close her eyes, opening them and laughing aloud when that particular professional starts to leave because he or she thinks that X is tired. This evidence is of a child who clearly has been able to enjoy her life and both give and receive pleasure and affection.
67. The 2nd Respondent’s evidence is not wholly positive or unrealistic in respect of X’s situation and the burdens that she has had to bear. He acknowledges that there have been and will continue be times in hospital which are confusing and even frightening, such as the approach of a doctor which will frequently signal to her that a procedure may follow. His evidence is that periods of being unsettled appear minimal. Nonetheless it is understandable if his view, of the persistent pain and suffering that X has and is suffering from, particularly more recently when she has required substantial pain relief, is affected by his desire to find the best for X. I accept that as the 2nd Respondent says there have been times when X has surprised medical professionals beyond their expectations of her ability to interact and respond, and that such interaction requires “a degree of commitment that it isn’t always possible for the professionals involved to give.” This must have been the case on PICU when X was being treated for acute deteriorations in her conditions and may go some way in explaining the disconnect or disagreement between the treating physicians and the parents, the impression that the 1st and 2nd Respondents had that their “views were dismissed out of hand”, and that some of the evidence filed by the Applicants was, at least from X’s parents’ point of view, inaccurate or partial, such as the circumstances surrounding X’s admission to the Portland from GOSH in 2017, and, more recently over a transfusion of irradiated blood.
68. Burdens. X is a 9-year-old girl who had haemolytic uraemic syndrome followed by a cardiac arrest. She has complex disability associated with multiple system disorders (taken from Dr Nadel’s report).
- i) Four limb cerebral Palsy with dystonia. GMFCS level 5
 - ii) Cortical Blindness
 - iii) Hypoxic ischaemic cortical damage
 - iv) Basal Ganglia Stroke
 - v) Gastro-oesophageal reflux disease
 - vi) Haemolytic uraemic syndrome - led to renal failure treated with renal transplant

- vii) Intestinal failure requiring hemicolectomy
 - viii) Previous Pancreatitis
 - ix) Laparoscopic Cholecystectomy March 2019
 - x) Subclavian vein thrombosis
 - xi) Lymphoedema due to venous insufficiency
 - xii) Intestinal failure, currently on full TPN, nil by gastrostomy.
69. Dr Nadel assessed X on Sunday 28th June 2020 on PICU and found her to be comfortable in her bed on the ward. Her current respiratory status was that she was comfortable at rest, she was receiving 30% inhaled oxygen by way of High Flow Nasal Cannula (Optiflow) delivered at 60litres/minute. She was warm and well perfused; her chest and abdominal examination were unremarkable apart from multiple chest scars from previous line and drain insertions and a midline abdominal scar. She had a gastrostomy in situ, through which she has a jejunal tube in place through which she is receiving 5mls/hour of feed. The remainder of her feed is given as parenteral nutrition via a double lumen Hickman Line placed on the left side of her chest.
70. Most noticeable to Dr Nadel on observation was X's "*grossly swollen upper right arm and shoulder with discolouration extending to the back and down to her elbow, with some redness and swelling extending across the anterior chest wall on the right.*" The wound was covered with a VAC dressing and drainage, on the upper/outer aspect of X's shoulder. On examination Dr Nadel found the shoulder was warm to touch, and indurated, but not obviously grossly tender, but both the bedside nurse and the 2nd Respondent, who was present, said that that X experienced some discomfort when the right arm was moved. X had her eyes closed during most of the examination and did not stir except on a few occasions when she opened her eyes. X was not obviously aware of Dr Nadel's presence but on one or two occasions she appeared to stir during the examination of her abdomen, she was not obviously distressed. Her father was talking to her while she was examined.
71. X was in receipt of pain relief in the form of a morphine infusion during this examination and assessment, which had been started the preceding Wednesday following a night when X was obviously distressed and awake for more than 4 hours. She was started on 5mcg/kg/hour, but became very sleepy on this dose, so it was reduced to 2.5mcg/kg/hour, which appeared to allow her to be a little more wakeful. In addition X had also started to be treated with a selection of broad-spectrum antibiotics because she was growing Pseudomonas bacteria from her lungs, her urine, and most recently from the wound on her right arm. She had a rise in her inflammatory markers (CRP) last weekend, and since the newer antibiotics were started, there has been a reduction in her CRP. At that time, the rest of X's blood count was within acceptable limits.
72. On the 28th June X's renal function was still markedly abnormal and her latest blood urea was around 18 and creatinine around 130 which had been fairly static over the last few days and there was concern that she may be a little dehydrated, so her fluids

had been liberated recently. She remained on a large dose of furosemide (diuretic) to maintain adequate fluid balance, and it was noted that she has lost a considerable amount of excess fluid over the last few weeks, with her latest weight around 36kg. Her treating doctors had told Dr Nadel that there is a delicate balance with X's fluids, between fluid overload, leading to fluid accumulation in her lungs, and dehydration leading to worsening renal function. In other words, as has been observed above in this judgment, the treatment of one X's co-morbidities had a deleterious effect on one or other of her interlinked conditions.

73. Dr Nadel observed that X was also on a cocktail of other medication including diazepam, clonidine, chloral, and gabapentin to try to control her dystonia, which primarily causes her problems when she is distressed due to pain or secretions. On that examination X's respiratory function appeared to be improving and she had less respiratory distress, and apart from a slightly increased respiratory rate, did not seem to be working hard to breathe. There appeared to be an objective improvement in her oxygen requirement and work of breathing over the past few days. X's secretions were not thick or troublesome, able to be cleared adequately with roughly hourly oral suction. In the opinion of Dr Nadel (and as proved to be the case) X's Optiflow could be weaned slowly and she would probably tolerate low flow nasal cannula oxygen. Tellingly, in respect of the decisions that remain to be made by this court, Dr Nadel observed that while a nasal cannula might be more acceptable to X, as high flow nasal cannula oxygen can sometimes be less well tolerated, she seemed to be comfortable and not distressed by her current treatment.
74. As submitted by counsel for the 1st and 2nd Respondents X *"is a child with many difficulties, but that is not all she is. She is, first and foremost, a child, a daughter, a sister, loving, and much loved."* There can be no doubt that this is true. X, when well enough and at her best, is clearly a delightful and engaging child. Nonetheless as we have seen X has complex conditions and with those conditions are associated burdens, while the combined medical opinion is that her life expectancy is short and that it is likely that there will be a continued deterioration in her overall condition it is not said, nor would it be accurate to say that, to use Dr Nadel's phrase, X was actively dying. That she will be at some time in the future cannot be denied but that point has not, as yet been reached.
75. At paragraph 22 of their closing submissions the Applicant says that there has been no sustained or material improvement in X's underlying condition. That is a statement that begs questions and fails to recognise that X has, in fact, had multiple complex clinical problems as part of her underlying condition for much of the past seven and more years during which she has had more than one acute crisis which has necessitated her admission to intensive care. This most recent admission to PICU has assisted X to recover from an acute crisis so that she is medically ready to be discharged back to a ward, which I understand happened on Monday 6th July 2020, this is surely the aim of intensive care treatment. X's condition has since fluctuated and there is every reason to believe it will continue to fluctuate. Ceilings of care have been agreed and the questions that remain in respect of the provision of Optiflow and re-admission to intensive care are set out previously in this judgment.

Conclusions

76. Optiflow. The elision of the provision of Optiflow with re-admission to PICU on the part of the Applicant was unattractive and did little to advance their case. As Dr Nadel observed if Optiflow would be of benefit to X and in her best interests and it is only available on PICU then she would have to be readmitted to receive it. As has been set out above the independent medical evidence has established that Optiflow is not a particularly burdensome treatment. The evidence of X's father was that there could be a benefit to X if it were to be provided for some simply reversible cause of respiratory distress such as some extra secretions that had not been cleared. This was supported by Dr Nadel who also said that if there was respiratory distress because of an intercurrent viral infection, it could be a benefit. It was possible, he said, that its use could get her over some minor deterioration and provide some relief. It is clear that there are possible benefits and that the burdens of such treatment are relatively minimal, X has been seen by the independent expert Dr Nadel to tolerate Optiflow and the balance is that it is in this child's best interests in some circumstances.
77. Adopting the formula put forward on behalf of X's parents and supported by her guardian X, will be provided with Optiflow to alleviate symptoms of respiratory distress in the event that, in the opinion of the senior clinician at the bedside, and following consultation with X's parents:
- i) There is a realistic prospect that Optiflow will ameliorate X's symptoms of respiratory distress and increased work of breathing,
 - ii) There is a realistic prospect that Optiflow will produce an improvement in Helene's respiratory function such that she will return to her pre-deterioration baseline.
78. In the event that X is provided with Optiflow, this will be discontinued, following consultation with X's parents:
- i) If her condition improves such that she no longer requires ventilatory support,
 - ii) If, in the opinion of the senior clinician at the bedside, X shows signs of distress or discomfort as a consequence of receiving Optiflow,
 - iii) If X's respiratory function continues to deteriorate, despite treatment, such that she requires escalation of ventilatory support to either CPAP, BiPAP or invasive ventilation
 - iv) If X's respiratory function has not improved after treatment with Optiflow over a period of one week [7days].
79. Following consultation with X's parents, X will not be provided with Optiflow:
- i) As an alternative to CPAP, BiPAP or invasive mechanical ventilation,

- ii) If, in the opinion of the senior clinician at the bedside, she has developed severe respiratory distress and/or she is actively dying,
 - iii) For more than two weeks [14 days].
80. Re-admission to PICU or intensive care. The relevant evidence and consideration of the burdens and benefits of re-admission to PICU or intensive care are set out above and I do not intend to repeat them. The Applicant Trust's own expert from whom they sought a second opinion, Dr Inwald, agreed that it would not be unduly burdensome to re-admit X to PICU. There is, in fact, no evidence that X is particularly disturbed by the environment of PICU. The Applicant has not identified any other burdens of re-admission to PICU but relies on a presumption that re-admission to PICU is inconsistent with a palliative care plan. While it can be seen that this will often be the case each plan of symptom control should be tailored to each individual child and it is hard to envisage that an effective exclusion from PICU or intensive care is either inevitable or acceptable. Given the fluctuations and unpredictability of X's condition overall and mindful of the complexities of her condition it cannot be in her best interests to make the declaration sought by the Applicant Trust and I decline to do so. It is not possible to say on the evidence that it will not be in X's best interests to be re-admitted to PICU to receive Optiflow or other treatment which may be considered of benefit to her and in her best interests within the confines of the ceilings of treatment already agreed.

Reporting restrictions order.

81. The court has been provided with written arguments as to the extent of any reporting restriction order. I have read the argument's and submissions filed on behalf of the parties with care, including that submitted on behalf of the Applicant Trust by Dr S. There is no need for me to rehearse and repeat the case law set out in those documents as there is no dispute as to the law which applies and I have been reminded of the Court of Appeal decisions in 2017 (along with more recent decisions) in respect of well publicised cases and the effects on treating staff and others employed by the Applicant Trust and in Liverpool. There is no dispute that the names of the child, her family and all the treating physicians should be anonymised. The judgment will be published as soon as it is handed down.
82. There has been no at all adverse or otherwise publicity that has been attracted by this case and the 1st and 2nd Respondents have not sought any publicity or published any comments on social media. The Applicant has not provided any compelling evidence that to name Great Ormond Street Hospital as the relevant NHS Trust and treating hospital will of itself will result in any risk to and of its personnel or that there is any imminent risk of harm to any members of staff or any medical professionals connected with this case who have been involved with X's care or treatment either in the past or at present.
83. There is simply no salient evidence in this case of any potential or likely negative attention from the public or the media. There has been no public and/or media campaign in relation to X, as occurred in some other relatively recent cases concerning withdrawal or withholding of treatment from young children. There is no evidence that naming the Applicant Trust will, in fact, be likely to impact on the clinicians caring for X or for other children in the hospital, other than a generalised

risk of adverse comment aimed at the Applicant Trust as an entity possibly based on previous publicised cases. There is a risk that on publication of the judgment there may be some publicity and possible negative comment online or elsewhere on social media but the level of anonymity should reduce any risk to individuals considerably.

84. In reaching this decision I am mindful of the need for transparency and of the judgment of the President of the Family Division in *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164, when at paragraph 102 he said, “*The manner in which social media may now be deployed to name and pillory an individual is well established and the experience of the clinicians treating child patients in cases which achieve publicity, such as those of Charlie Gard and Alfie Evans, demonstrate the highly adverse impact becoming the focus of a media storm may have on treating clinicians. The need for openness and transparency in these difficult, important and, often, controversial cases is critical but can, in the judgment of the court, be more than adequately met through the court's judgments without the need for identifying those who have cared for Midrar with devotion since September 2019.*”
85. This judgment has anonymised all the treating physicians along with X and her family. The need to balance open justice and for the courts to be transparent has been better analysed and fully amplified in previous cases. If the arguments advanced for and on behalf of the Applicant were to be accepted in this case and applied to all cases involving the Applicant Trust, the result would be that the Trust would always remain anonymous. This case falls to be decided on its particular facts and there is no evidence in this case of the kind of distressing, intemperate and intimidatory publicity and social media comment that has occurred in other cases. It in these circumstances, where the evidence of actual risk to individuals employed by the Applicant is negligible, it would be disproportionate to restrict the reporting further than is provided for in this judgment and the reporting restrictions order will be made in accordingly.
86. This is my judgment.