Covid-19 Protocol: This hearing was conducted in public and in person, but this judgment was handed down at a remote hearing, in public and by circulation to the parties' representatives by email, and release to BAILII. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the Applicant's witnesses and any individual having day-to-day care of or medical responsibility for the Child (the First Respondent) at the Applicant Trust 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.

Neutral Citation Number: [2021] EWHC 25

Case No: FD20P00135

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 08/01/2021

Before:

Mr Justice Poole

- -

Between:

GUY'S AND ST THOMAS' CHILDREN'S NHS FOUNDATION TRUST **Applicant**

and

(1) PIPPA KNIGHT
(By an officer of Cafcass and her Children's Guardian)

(2) MS PAULA PARFITT

Respondents

- -
- -

Michael Mylonas QC (instructed by **Hill Dickinson LLP**) for th**e Applicant**
Neil Davy (instructed by **Cafcass Legal Services**) for the **First Respondent**
Vikram Sachdeva QC and Victoria Butler-Cole QC (instructed by **Sinclairs Law**) for the **Second Respondent**

Hearing dates: 14-18 December 2020

- -

APPROVED JUDGMENT

Mr Justice Poole:

Introduction

1. Pippa Knight is a much loved five year old girl. Her father died three years ago but she has the most dedicated and loving support of her mother, Paula Parfitt, her older brother, aged 7, and her maternal grandparents, uncle, and aunt. Together they form what Ms Parfitt describes as "powerful unit of strength for her and for each other."

2. That strength has been needed. Pippa is gravely unwell. She has severe brain damage and has been kept alive by mechanical ventilation through a nasal endotracheal tube in the paediatric intensive care unit at the Evelina London Children's Hospital since January 2019. Expert neurologists and intensivists agree that she probably feels no pain and experiences no pleasure, that she is not conscious of her environment, and that there is no prospect of improvement in her condition. The NHS Trust responsible for Pippa's care and treatment, whose doctors, nurses and therapists have exercised exceptional skill in looking after her, considers that she has been through enough. It asks this court to exercise its inherent jurisdiction to declare that it is lawful and in Pippa's best interests that:

    a. She should not be provided with a tracheostomy.
    b. Mechanical ventilation should be withdrawn.
    c. There be clearly defined limits on the treatment provided to Pippa after that withdrawal of ventilation, with the effect that she would be allowed to die.

3. Ms Parfitt opposes the Trust's application. The evidence shows that there have been many meetings between Ms Parfitt and the treating team. She is aware of all the expert medical opinions that have been given in this case, but unlike the Trust, she believes that Pippa has made some progress since January 2019, that she has awareness of her family and can derive pleasure from being with them and from touch and other sensations, and that it is in her best interests to continue on long term ventilation. In reliance on expert evidence, including from Dr Colin Wallis, Consultant Respiratory Physician, Ms Parfitt proposes that Pippa should now undergo a trial of portable ventilation, a tracheostomy, and management in a transition unit with a view to her being discharged from hospital, to be cared for at home.

4. Pippa is represented by her children's guardian, Lauren Doyle of the Cafcass High Court Team. After much careful consideration she supports the Trust's application.

5. Ms Parfitt does not seek anonymity for herself or for Pippa. The hearing before me was held in public and in person, with two witnesses giving evidence by video link. The parties and the court have had the benefit of experienced Counsel: Mr Mylonas QC for the Applicant, Mr Davy for the First Respondent, and Mr Sachdeva QC and Ms Butler-Cole QC for the Second Respondent. I am grateful to them and to their instructing solicitors for the care and skill they have exercised in presenting this case.

6. The dispute as to whether continuing ventilation should or should not be given to Pippa has been brought to the court for determination because Ms Parfitt and those who are treating Pippa have been unable to come to an agreement. The Trust has carried out best interest reviews. It has sought second opinions from independent consultants. Its Ethics Committee has given its opinion on whether long term ventilation is in Pippa's best interests. Mediation has taken place but was not successful. This case is of an

exceptional nature – very few children are in Pippa's condition – and it is the exceptional cases that tend to come before the courts. The Trust's application was made in March 2020 but it has taken several months to arrive at a final hearing. This is in part due to the Covid-19 pandemic, but also because of the nature and extent of the expert evidence in the case. On 22 July 2020, Judd J gave permission to the Second Respondent to rely on six expert witnesses. One of those, Dr Wallis, proposed a trial of portable ventilation with a view to transferring Pippa home. The feasibility of that proposal, and the conditions under which a trial should be conducted, have taken time to investigate.

7. Since the parties bring Pippa's case to court, the court must make a determination – it has a duty to do so. The court is independent of the Trust, of the NHS, and of Ms Parfitt. The court's power is to decide whether a course of treatment is lawful or unlawful. It has no power to require doctors to carry out a medical procedure against their professional judgment. The court's decisions are not based on what the particular judge would decide for themselves, or what outcome they would want for their own loved ones. Nor are the judge's own ethical or religious beliefs relevant. Rather, the court seeks to apply the law to the facts of the individual case. The question for the court is what is in Pippa's best interests.

8. On the first afternoon of the hearing, Ms Doyle and I visited Pippa on the PICU at the Evelina. Her mother was where she can usually be found: at her daughter's bedside. I had expected that any visit would be by a video link of some kind, given the current Covid-19 pandemic, but Ms Parfitt wanted me to attend in person and the Trust was happy to accommodate the visit with suitable safeguards being taken. The purpose of the visit was not to gather evidence, but to see Pippa in the environment in which she is cared for. The visit helped to connect the forensic process within the court room with the real circumstances in which Pippa and her mother find themselves.

9. In court, I heard powerful oral evidence from Ms Parfitt. I have been provided with written evidence from Ms Doyle, from a number of medical and nursing personnel at the hospital, and from the Head of Placements for Children and Young People at the Clinical Commissioning Group for Pippa's home location. I have also had the benefit of extensive expert evidence as follows:

    a. From Dr A, a Paediatric Intensive Care Consultant who is Pippa's lead consultant and who has been involved in her care throughout her time at the Trust's PICU, and from Dr Playfor, a Consultant Paediatric Intensivist instructed by the Second Respondent mother. They have produced a joint statement following discussion. I heard oral evidence by video link from them both.

    b. From Dr B, Consultant Paediatric Neurologist, who has been the lead Consultant Neurologist involved in Pippa's care at the hospital, and from Dr Spinty, Consultant Paediatric Neurologist instructed by the Second Respondent mother. Again, those two experts have produced a joint statement following discussion. Such is the extent of agreement between them that the parties did not need to call them to give oral evidence.

   c. From Dr C, Respiratory Consultant, who has led Pippa's respiratory care at the hospital, and from Dr Wallis, Consultant Respiratory Paediatrician instructed by the Second Respondent mother. They too have produced a joint statement following discussion. I also heard their oral evidence.

   d. Ms D, physiotherapist, and Ms E, occupational therapist from the Trust, and Ms Stevenson and Mr Chakraborty, respectively physiotherapist and neuro-rehabilitation occupational therapist instructed by the Second Respondent mother. These four witnesses produced a joint statement together following discussions. They did not give oral evidence.

   e. Ms F, Clinical Specialist Paediatric Respiratory Physiotherapist employed by the Trust, and Dr Chatwin, Clinical Specialist Paediatric Respiratory Physiotherapist, instructed by the Second Respondent mother. They also have produced a joint statement following discussions. They also gave oral evidence.

The names of the medical and other personnel at the Trust have been anonymised following a reporting restrictions order made in July 2020. The volume of expert evidence reflects both the complexity of Pippa's care needs, and the depth of investigation that has been carried out to help the court to determine the difficult issues which it must now address.

Background

10. The background to this application is heart-rending. Pippa was born on 20 April 2015. As a very young child she was affectionate, reaching out to her parents and others for cuddles. She had a strong bond with her brother whom she idolised. She developed normally until December 2016 when her mother took her to Medway Hospital because she was unwell. She deteriorated overnight and began to suffer seizures. She was transferred to the Paediatric Intensive Care Unit ("PICU") at St George's Hospital, London, and was diagnosed with acute necrotising encephalopathy ("ANE"), a rare condition in which an acute febrile disease, usually a viral infection such as influenza, is followed rapidly by seizures, disturbance of consciousness, and ultimately brain damage (encephalopathy). Pippa remained on the PICU until 10 January 2017, when she was moved to the paediatric ward. A month later she was transferred back to Medway Hospital, and after another month she was transferred to a neuro-rehabilitation unit where she remained for a further three months. On discharge home Pippa was severely compromised. She had a four-limb motor disorder with a predominant dystonia. She required nasogastric tube feeding and was thought to have cognitive impairment.

11. Pippa went home on 9 June 2017 to be looked after by her mother. Her father had lost a young son from a previous relationship to meningitis. He found it difficult to cope with the fact that another of his children was suffering so grievously. A few days after Pippa's discharge home, he took his own life. Ms Parfitt had to cope not only with her own bereavement, but with two bereaved children, one of whom was newly discharged from rehabilitation and severely disabled.

12. In late February 2018 Pippa required in-patient care at Medway Hospital for 18 days following a viral infection, but she did not require intensive treatment and she was able to return home. She made progress under the care of her mother at home. She gradually regained some strength and could walk a few metres with a walking frame (her left leg was weaker and she had difficulties with balance). She regained the ability to crawl and she could ride a tricycle with support. She had limited verbal communication but was interactive in play.

13. Tragically, in January 2019 ANE struck again. On 14 January 2019 Pippa was admitted to Medway Hospital with a fever but she deteriorated. Her Glasgow Coma Score fell to 3/15 indicating a catastrophic loss of consciousness. She was transferred to the Applicant Trust's care on 15 January 2019 and admitted to its PICU where she was ventilated and given life support. Once again Pippa survived, but this time there has been no recovery of the kind she made after her first episode of ANE. She has remained on mechanical ventilation and is still a patient on the PICU at the Evelina nearly two years later.

14. Pippa's mother, Ms Parfitt, lives in hospital accommodation and spends as many as sixteen hours most days by Pippa's bedside. Pippa currently receives video calls from her brother and grandparents, and Ms Parfitt's brother and grandmother often sit with Pippa for long hours when Ms Parfitt is resting. The fact that Ms Parfitt has not been wholly ground down by her experiences is a tribute to her resilience and dedication. As Pippa's children's guardian Ms Doyle has said, she is "the most committed of mothers with a strength and mindset that I cannot comprehend."

Issues for the Court to Determine

15. The Trust seeks three declarations as set out above. Mr Mylonas QC for the Trust began his closing written submissions with the following:

    > "There is one primary issue for the Court's determination – is it in Pippa's best interests (and therefore lawful) for life sustaining treatment to be withdrawn?"

    In their opening position statement, Mr Sachdeva QC and Ms Butler-Cole QC for Ms Parfitt, contended that the choice for the court is "death now in hospital, or death in the future after a period at home." In fact, the questions for the court are about treatment and the withdrawal of treatment, not about choosing death, even if death is the inevitable consequence of withdrawal of ventilation. In *Airedale NHS Trust v Bland* [1993] AC 789, Lord Goff of Chieveley (with whose judgment Lord Keith of Kinkel and Lord Lowry expressly agreed) pointed out that,

    > "the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment." [p 868]

The Second Respondent's case is not that it is in Pippa's best interests to be transferred home with a view to withdrawal of ventilation, but rather that steps should be taken to determine whether long term ventilation can be provided at home. As such, "death in the future after a period [of long term ventilation] at home" is not a choice currently available, because no-one yet knows whether Pippa can be given ventilation at home for anything beyond a few hours, or a few days at most. The Second Respondent's closing written submissions better reflect this fact. They began:

> "This case is about whether Pippa should be permitted to undergo a trial which will reveal whether she is sufficiently stable to be sent home to spend her last weeks or months in the company of her devoted mother and brother."

16. In my judgement, it is necessary to determine Pippa's best interests, and whether to make the declarations sought, in the context of three available options:

    A. Continuation of life-sustaining mechanical ventilatory support and treatment within a PICU setting.
    B. A trial of portable ventilation with a view to transition to long term ventilation and life sustaining treatment at home.
    C. Withdrawal of life sustaining mechanical ventilatory support.

    Neither Counsel for the Second Respondent nor any of the clinical or expert witnesses have contended that option A would be in Pippa's best interests, but in my judgement it is necessary for me to consider it because,

    (i) Pippa's mother made it clear in her evidence that she would prefer option A to option C.

    (ii) Even if I determine that option B is in Pippa's best interests, the trial of portable ventilation might well fail, or the provision of home ventilation might otherwise become impossible to achieve. In that case, it is likely that the parties would remain in dispute about whether continued ventilation in the PICU was in Pippa's best interests. I should note that the likelihood of such a dispute may have reduced following the hearing. The evidence given was that the initial trial would take two weeks, but that the transition process before home care could be attempted could take at least six months. In closing submissions on behalf of Pippa's mother, Counsel stated,

    > "Reflecting further since the conclusion of the oral evidence, Ms Parfitt has informed her solicitor that if Pippa passed the trial but in 6 months' time there was no real progress towards a return home or if Pippa's condition had stayed the same or deteriorated, she would consider consenting to withdrawal of ventilation."

    Even given Ms Parfitt's new position - which is that she would consider consenting to withdrawal of ventilation, not that she would consent - it seems to me that there would remain the likelihood of a dispute about Pippa's best interests in the future. Ms Parfitt already disagrees with the healthcare professionals' views about the progress of Pippa's condition, and there would be ample room for further disagreement about Pippa's condition during the transition process, and whether "real progress" had been made towards a return home.

(iii) It would in principle be open to the court to find that neither option B nor option C were in Pippa's best interests, but that option A was. All agree that the quality of medical and nursing care that could be afforded to Pippa at home would be lower than could be given in a PICU setting. The court is not bound to accept the opinions of the medical experts and could in principle find that long term ventilation is in Pippa's best interests but only if provided in the optimal setting of the PICU.

17. As for option B, in my judgment I have to consider Pippa's best interests as they are now. I cannot know the outcome of a trial of portable ventilation or of the potentially long and detailed process of transition to home care. It is not possible to make multiple declarations about her best interests applicable to the many differing circumstances that might arise as the trial and then the transition process progressed. However, the evidence does allow me to consider:
    a. The nature of the end goal of long term ventilation and life sustaining treatment at home.
    b. The prospect that the trial and transition process would result in the end goal of home care being achieved.
    c. What that process would entail for Pippa: what would be the means by which the end would be achieved.

By considering those factors, the court can make an assessment of whether it is in Pippa's best interests to embark upon the trial and transition process – option B. It would be wrong in my judgment to focus exclusively on the very first step in that process. The initial trial of portable ventilation is not an end in itself, it is a means to an end, or, more precisely, a necessary but not sufficient means to the end of providing Pippa with life sustaining treatment at home. If it would not be in Pippa's best interests to reach the destination, then it is unlikely to be in her best interests to embark on the journey.

18. Option A is not a hypothetical option, it is the ongoing reality. Option B is an available option and is urged upon the court by the Second Respondent. The Applicant and First Respondent submit that ongoing long term ventilation is not in Pippa's best interests, wherever it may be given, and that Option C is in her best interests. These are the options available that I should consider when assessing Pippa's best interests.

19. In the remainder of this judgment I shall consider the legal framework in which the court's determinations are to be made; summarise the evidence as to Pippa's condition and management; consider the steps that would need to be taken to discharge her into home care, the chances of those steps being successful, and what home care would comprise; and then examine Pippa's best interests in the context of the three options I have identified.

The Law

20. The law applicable to decisions of the kind this court is required to make in respect of a young child, has been set out in numerous cases. The key principles articulated by the Court of Appeal in *Portsmouth Hospitals NHS Trust v Wyatt and Anor* [2005] EWCA Civ 1181, and by Holman J in *An NHS Trust v MB* [2006] EWHC 507, continue to guide the courts today. They are that,

    i) The judge must decide what is in the best interests of the child.

    ii) In making that decision the welfare of the child is the paramount consideration.

    iii) The judge must look at the question from the assumed point of view of the child.

    iv) There is a strong presumption in favour of a course of action that will be likely to preserve life but that presumption is not irrebuttable.

    v) The term "best interests" encompasses medical, emotional and all other welfare issues.

    vi) The court must consider the views of the doctors and parents.

    vii) Each case will turn on its own facts.

    viii) The court must conduct a balancing exercise in which all relevant factors are weighed. This is not a mathematical exercise but it is an objective one.

21. More recently, in *Re A (A Child)* [2016] EWCA Civ 759, the Court of Appeal said at [31]:

> “Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 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 from paragraph 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."

22. In *An NHS Trust v MB*, Holman J said this of parental views,

> “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.” [16]

To parents of a child whose life is in the balance, this may sound a harsh doctrine, but it seeks to emphasise that the child’s welfare is paramount. When a child’s parents and the medical personnel treating a child disagree about whether certain treatment is in a child’s best interests, neither has a veto – the court, taking an independent and objective view of the evidence, is required to decide what is in the child’s best interests. Nevertheless, authority from the European Court of Human Rights does suggest that parental wishes are a factor that should be taken into account. Pippa has a right to life under Article 2 of the European Convention on Human Rights. Art 2 imposes a positive obligation on the state to protect life but, although that is a fundamental right, withdrawal of life sustaining treatment is not a contravention of Art 2 if certain requirements are met. In *Gard and Others v. the United Kingdom* - 39793/17 (Decision [2017] ECHR 605 (27 June 2017) the ECtHR identified those requirements:

> "[80] In addressing the question of the administering or withdrawal of medical treatment … the Court has taken into account the following elements:
>
> - the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2;
>
> - whether account had been taken of the applicant's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel;
>
> - the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests (Lambert and Others,[1] § 143)."

Reading the judgment as a whole, the ECtHR was not entirely clear, in my respectful view, as to whether decision-makers should have regard to the wishes of "persons close to" the individual, their evidence as to what the individual's wishes were or would be, and/or their views as to what is in the individual's best interests. However at [69] the ECHR did indicate, but did not determine, that in the case of a young child who had never been able to express views or wishes, their parents' "status" might be afforded greater weight, and at [80] the ECtHR expressly referred to need to take into account the wishes of those close to the individual concerned.

23. Pippa and Ms Parfitt each have Article 8 rights to family life, interference with which can only be justified if in accordance with the law and necessary in a democratic society for, amongst other things, the protection of the rights and freedoms of others.

24. The burden of proof is on the Applicant who seeks the declarations set out above, the standard of proof being the civil standard, on the balance of probabilities.

25. In cases where the individual concerned is in a permanent or persistent vegetative state, there are two strands of authority as to whether the court is able to, and should, engage in any balancing exercise of benefits and burdens when considering best interests. In *Airedale NHS Trust v Bland* [1993] AC 789, Lord Goff held at [868F]

> "… a distinction may be drawn between (1) cases in which, having regard to all the circumstances (including, for example, the intrusive nature of the treatment, the hazards involved in it, and the very poor quality of the life which may be prolonged for the patient if the treatment is successful), it may be judged not to be in the best interests of the patient to initiate or continue life-prolonging treatment, and (2) cases such as the present in which, so far as the living patient is concerned, the treatment is of no benefit to him because he is totally unconscious and there is no prospect of any improvement in his condition. In both classes of case, the decision whether or not to withhold treatment must be made in the best interests of the patient. In the first class,

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[1] Lambert and Others v. France [GC], no. 46043/14, ECHR 2015

> however, the decision has to be made by weighing the relevant considerations.
>
> … By contrast, in the latter class of case, of which the present case provides an example, there is in reality no weighing operation to be performed. Here the condition of the patient, who is totally unconscious and in whose condition there is no prospect of any improvement, is such that life-prolonging treatment is properly regarded as being, in medical terms, useless. …
>
> But for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family—a distress which reflects not only their own feelings but their perception of the situation of their relative who is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination."

26. The position that for a patient in a PVS, the futility of the treatment justifies its termination, and there is in reality "no weighing operation to be performed", was adopted by Hayden J in *M v N* [2015] EWCOP 76:

> "45. It is well established that if I conclude Mrs. N to be in MCS any evaluation of her best interests must involve a proper identification of the advantages and disadvantages of each proposed course. This approach is conveniently referred to as the 'balance sheet', a test articulated, in this context, by Thorpe LJ in *Re A (Male Sterilisation)* [2000] 1 FLR 549. …
>
> 47. By contrast, if I conclude that Mrs. N had no awareness at all, i.e. that she was in VS, the 'balance sheet' analysis does not apply, the diagnosis itself establishing the futility of further intervention. Definitive authority for this proposition is found in the judgment of Sir Mark Potter, in: *A Hospital v SW* [2007] Med LR 273 at [28]:
>
> "Whereas in most cases relating to the propriety or desirability of treatment for mentally incapacitated patients, it is requisite to draw up a balance sheet of the benefits and dis-benefits of providing medical treatment...it was made clear in the Airedale case that there is effectively no balancing operation to be performed where a person has a definite diagnosis of PVS, the futility of the treatment justifying its termination".

> 49. Were I to agree with Professor Wade that VS is the correct diagnosis here it would require me to endorse an opinion which steps outside the recently drafted and widely respected guidelines. …. I am bound to say, that for my part, where some level of awareness remains, however limited it may be, I instinctively consider that in such cases (whatever the label given to the condition) a decision to withdraw treatment should only be made after a full analysis of P's best interests. If I had accepted Professor Wade's conclusion it would have followed, inevitably, that no such analysis was required. It is, as I have stated, axiomatic that if P is in a vegetative state, treatment is futile."

27. An alternative strand of authority recognises that even for a patient in a PVS, for whom treatment is medically "futile" there are some considerations to be weighed in the balance when considering best interests. Lord Goff himself referred in *Bland* to the invasiveness of treatment, and the indignity caused to a patient. In the same case, in the Court of Appeal, Lord Hoffman said at [826F]

> "… the sanctity of life is only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular for his right to choose how he should live his own life. We call this individual autonomy or the right of self-determination. And another principle, closely connected, is respect for the dignity of the individual human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person."

28. Lord Browne-Wilkinson in Bland advised some caution in weighing what he called "impalpable factors":

> "The position therefore, in my view, is that if the judges seek to develop new law to regulate the new circumstances, the law so laid down will of necessity reflect judges' views on the underlying ethical questions, questions on which there is a legitimate division of opinion. By way of example, although the Court of Appeal in this case, in reaching the conclusion that the withdrawal of food and Anthony Bland's subsequent death would be for his benefit, attach importance to impalpable factors such as personal dignity and the way Anthony Bland would wish to be remembered but do not take into account spiritual values which, for example, a member of the Roman Catholic church would regard as relevant in assessing such benefit. Where a case raises wholly new moral and social issues, in my judgment it is not for the judges to seek to develop new, all embracing,

> principles of law in a way which reflects the individual judges' moral stance when society as a whole is substantially divided on the relevant moral issues. Moreover, it is not legitimate for a judge in reaching a view as to what is for the benefit of the one individual whose life is in issue to take into account the wider practical issues as to allocation of limited financial resources or the impact on third parties of altering the time at which death occurs."[879H].

29. Notwithstanding this warning, judges have drawn "impalpable factors" into the balance. *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), a case to which I shall return later in this judgment, concerned a five year old girl who was unable to feel pleasure or pain, but who had some minimal awareness. MacDonald J held that factors such as human dignity and the benefits of being cared for by a loving family as opposed to by hospital personnel in an intensive care unit, ought to be weighed in the balance even for a child with very limited conscious awareness.

Professional Guidance

RCP Guidance

30. The Royal College of Physicians published National Clinical Guidelines: "*Prolonged disorders of consciousness following sudden onset brain injury"*, the report of a working party, in 2020. The patient group comprised individuals aged 16 or over. Nevertheless, given that these guidelines are endorsed by a wide range of bodies including the Faculty of Intensive Medicine, it is helpful to have regard to them, and in particular the definitions used:

> "Vegetative state: a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours. VS is characterised by complete absence of behavioural evidence for self or environmental awareness.
>
> Minimally Conscious State: a condition of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated'. MCS is characterised by inconsistent, but reproducible, responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings."

VS or MCS can be continuing, chronic or permanent. A permanent VS, or MCS can only be diagnosed by a suitably qualified consultant physician who meets the criteria for an 'Expert PDOC Physician' and "after the patient has been in chronic VS or MCS for at least 6 months in the absence of any measurable trajectory of change."

RCPCH Guidance

31. The Royal College of Paediatrics and Child Healthcare published the document, "*Withholding and Withdrawing Life Saving Treatment in Children*" in 1997. In 2015 revised guidance was published under the title, "*Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice.*"[2] The authors issue a caution as follows:

> "We emphasise two important points so as to avoid confusion:
>
> 1. This document sets out circumstances under which withholding or withdrawing life sustaining treatment might be ethically permissible—NOT circumstances under which such treatment must certainly be withheld or withdrawn.
>
> 2. The document describes situations in which individual children should be spared inappropriate invasive procedures—NOT types of children to whom appropriate procedures should be denied."

The guidance then sets out three sets of circumstances in which the RCPCH advises that treatment limitation can be considered "because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit". They are:

> "I When life is limited in quantity
>
> If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:
>
> A. Brain stem death, as determined by agreed professional criteria appropriately applied
>
> B. Imminent death, where physiological deterioration is occurring irrespective of treatment
>
> C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.
>
> II When life is limited in quality
>
> This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

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[2] BMJ Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1–s23

> A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
>
> B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
>
> C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.
>
> III Informed competent refusal of treatment
>
> Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST."

Although the terminology used is of "permanent" vegetative state, the witnesses in the present case have used the term "persistent" vegetative state. For the sake of consistency, I shall use "PVS" to refer to persistent vegetative state.

Pippa's Condition

32. Pippa's condition has been assessed at the Evelina over the nearly two years she has been a patient within its PICU. Longitudinal multi-disciplinary assessments have been performed to determine whether she is showing any signs of change. Numerous meetings have been held with Ms Parfitt, and with other family members to consider Pippa's condition. In 2019 the Trust made referrals for second opinions from a paediatric neurologist and paediatric intensivist at the Addenbrooke's Hospital in Cambridge. I have seen those opinions which largely accord with the expert opinions given to the court on behalf of the parties. All those experienced and highly qualified medical witnesses agree that, in summary:

    a. Pippa has suffered very severe brain damage as a result of ANE.
    b. She is in a persistent vegetative state ("PVS"). She has no conscious awareness of herself or her environment.
    c. On the balance of probabilities Pippa cannot experience pain or discomfort[3].
    d. On the balance of probabilities Pippa cannot derive any pleasure from her environment or interaction with others.

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[3] The paediatric neurologist from Cambridge did advise that children in Pippa's condition have the "capacity for pain" but he gave no evidence that Pippa herself could sense pain.

e. Pippa has random movements of her neck, head, and limbs. She has no purposeful movement. She shows no response to visual, auditory, or tactile stimulation.
f. She is wholly dependent on others for all her care.
g. She has no respiratory effort – she cannot breathe at all – and is wholly reliant on mechanical ventilation.
h. She has respiratory instability with frequent desaturations which require specialist nursing and physiotherapy interventions.
i. She is doubly incontinent.
j. She has cortical blindness.
k. Her condition has been static for well over a year and there is no prospect of any improvement.

Pippa's Neurological Condition

33. Dr G, Consultant neuroradiologist at the Trust says that MRI scanning in March 2019 reveals,

> "considerable brain tissue volume loss and shrinkage with mature (chronic) damage, chronic haemorrhagic damage and gliosis in the thalamus, basal ganglia and brainstem, including the widening of the cerebrospinal fluid (CSF) spaces around the brain."

EEG Telemetry has been performed, most recently over a 20 hour period at the end of September 2020. It revealed a wake-sleep pattern, but no evidence of any reactivity on visual, auditory, or painful stimulation.

34. Dr B and Dr Spinty agree the following evidence:

> "There are widespread destructive lesions of the brain including the brain stem, thalami and basal ganglia structures. These brain structures have a vital role in coordinating all neurological functions. There is also evidence of injury to the cortex. The injury has resulted in prolonged disorder of consciousness consistent with persistent vegetative state as defined in the RCP guidelines. She is totally dependent on the ventilator due to lack of respiratory drive and very abnormal brainstem function. We both agree that Pippa's neurological function is very severely impaired.
>
> …. Pippa has lost some vital parts of brain stem function due to the acquired injury. This is evident on clinical examination including the longitudinal multidisciplinary team assessments and on serial MRI brain scans. The acquired injuries have resulted in the need for lifelong ventilation and respiratory support. She will remain totally dependent on carers for the rest of her life. She has a four limb motor disorder and has lost

> multiple cranial nerve functions. We both agree that the brainstem functions will not recover."

They agree that,

> "Persistent vegetative state (PVS) is the correct description of Pippa's prolonged disorder of consciousness. She is not in a coma and we have no discernible behavioural evidence of self or environmental awareness to suggest that Pippa is in a minimally conscious state.
>
> … there are no viable treatments that would result in an improvement of her neurological status.
>
> … We agreed that long term ventilation will not change Pippa's neurological condition or long term prognosis. We agreed that there is no hope for a significant neurological recovery."
>
> "…. it is impossible to know at present whether Pippa is experiencing pleasure, discomfort, or pain. We have considered all the longitudinal investigations and reports including the latest from September 2020. We both agree that on the balance of probability, Pippa does not suffer discomfort, pain, or pleasure, but we are unable to exclude the possibility that she might experience discomfort, pain, or pleasure at some level.
>
> ... We both agree that Pippa's life is limited in quality with a severity of condition that is such that it is difficult or impossible for her to derive benefit from continued ventilatory support.

The Evidence of the Paediatric Intensivists

35. Dr A and Dr Playfor also agree on a great deal. They agree that:

    a. Pippa has made no progress since January 2019.
    b. There is no prospect at all of Pippa being able to survive in the future without ventilatory support and she would die very soon after extubation.
    c. "… on the balance of probabilities Pippa does not suffer any discomfort or pain from her current life – including the regular interventions that are required (such as deep suctioning of secretions)".
    d. "… on the balance of probabilities Pippa is not able to derive any pleasure from any source".
    e. Neither believes that "Pippa derives any personal benefit from prolonged ventilatory support".

36. Dr Playfor told the court that although he agreed that the possibility that Pippa could experience pain or pleasure could not be excluded, he would be very surprised if she had such capacity. He said in oral evidence that it was "difficult to think of circumstances where you could have more confidence that she cannot perceive pain or

discomfort – it is highly unlikely.” It was also “extremely unlikely that she experiences any pleasure from interaction with those around her and her environment”.

Agreed Evidence from Physiotherapists and Occupational Therapists

37. In their four-way joint statement, Ms D, Ms E, Ms Stevenson, and Mr Chakraborty recorded that they had made contact with Helen Gill-Thwaite and Karen Elliott, developers of the Sensory Modality Assessment and Rehabilitation Technique (“SMART”) assessment of patients with prolonged disorders of consciousness. They responded that they could not offer an assessment of Pippa because they did not have specialism in paediatrics and,

> “as you are aware SMART is currently not validated with children. Whilst we have developed SMART version 3 to accommodate the needs of children with specialist guidance from the Children’s Brain Injury Trust, Tadworth, it is not yet validated for this group. We have however, used this assessment in some medico legal cases, but only because the children have been older than 6 years old at the date of the index incident.”

Contact was then made with Helle Mills at Tadworth who is the most experienced SMART assessor at Tadworth having been accredited for 10 years, and who uses SMART to assess children. She responded:

> “I do unfortunately not feel a SMART assessment would be appropriate due to the child's young age at time of index incident (even when considering the latest incident at 3.9 years old) and therefore lack of development and ability to engage in the assessment at pre injury stage… I am concerned the child will not have the pre injury skills to engage in the assessment even if there is awareness.”

Nevertheless, the four witnesses agreed that,

> “Pippa has shown no consistent, repeatable, behaviour or purposeful movement to suggest that she has any conscious awareness to auditory, visual, tactile, proprioceptive or vestibular stimulation.”

38. Whilst much of the focus of the oral evidence has been on Pippa’s respiratory condition, these witnesses provide evidence in relation to some of Pippa’s other long term therapeutic needs:

> “Maintenance of range of movement and provision of equipment to offer variety in seating and positioning is possible in the home setting, providing that there is availability of equipment and sufficient trained carers to carry out safe transfers and position

> changes. Pippa currently requires three trained carers for all transfers (two for hoisting and one to maintain her airway).
>
> Children with special needs, in the community routinely stand in standing frames at home or special school on a daily basis. This would be possible for Pippa to achieve but would necessitate three trained carers to hoist and move Pippa onto a tilt table or standing frame whilst maintaining her airway and then at least two trained carers to stay with her for the duration of the stand to maintain her airway and head alignment."

Pippa's Respiratory Condition

39. Pippa has no respiratory drive – she cannot breathe for herself at all. She has been ventilated on the PICU since admission in January 2019. Unusually she remains ventilated via an endotracheal tube ("ETT") rather than a tracheostomy tube. A tracheostomy was offered in February 2019, which was standard practice given that neurological improvement was then anticipated and there would be a likelihood of long term ventilation. Ms Parfitt declined a tracheostomy on behalf of her daughter and now says that she did not fully understand why it was being offered. By May 2019 the paediatric neurologist from Cambridge, who was contacted for a second opinion, was advising that a tracheostomy was not in Pippa's best interests, but he would not have anticipated that Pippa would have remained ventilated on the PICU as long as she has been. Pippa is attached to a standard ventilator and her respiratory support is described as modest with baseline settings at peak inspiratory pressure (PIP) 17, positive end-expiratory pressure (PEEP) 5, and SiO_2 30%. However, those baseline settings are adjusted several times a day according to her physiological need. Dr C explained that the particular challenges with Pippa's respiratory condition are not related to ventilation in itself, but to her tendency to desaturate, that is, for her oxygen saturation to fall. In the PICU, the target is oxygen saturation of at least 92%. About 10 to 20 times per day, on average, Pippa's saturations fall to between 80% and 90%. With careful monitoring those changes are noted and acted upon. The reason Pippa desaturates is that she has poor oxygen reserve and a tendency for her lungs to collapse ("atelectasis"), and that secretions and saliva accumulate in her airway. Secretions are produced by cells in the lung tissue, saliva is produced in the mouth. She cannot swallow, she has no gag reflex, she cannot cough, and she has little movement. These factors combine to allow both secretions and saliva to collect in Pippa's airway, causing blockages. Because she has poor reserve, the blockages quickly cause decline in her oxygenation.

40. Dr C and Ms F both told me of the regime used to counter the blockages and desaturations. Regular respiratory physiotherapy is required. Pippa is frequently moved from her back to her side and vice versa. She is also moved into a special "bee" chair on a daily basis. For at least two hours a day Pippa is turned into a prone position, a manoeuvre which takes two, sometimes three, individuals to complete. I was told that Ms Parfitt assists and has become particularly expert at helping to move Pippa onto her front. The object of "proning" is to remove pressure on the back of her lungs so that her alveoli, the tiny pleural sacs, can take up oxygen and so build up her reserve. A cough assist machine, called a Clearway, is used two to three times a day, and sometimes a

fourth time if needed. This machine administers saline under pressure and then reverses the flow, simulating a cough, so as to encourage secretions to move up the airway from where they can be suctioned. In addition, a risky process called saline lavage is undertaken by a suitably qualified respiratory physiotherapist. This involves instilling large amounts of saline into the lungs, giving large breaths with the oxygen bag, turning the patient, and using manual techniques alongside the bag breaths and suction to clear secretions. Mouth suctioning is also performed throughout the day and night.

41. Even with these interventions, Pippa desaturates every 1 to 4 hours. Generally, these episodes are addressed by deep suctioning (the suction tube goes to just above her vocal cords), adjustments to the ventilator pressures, and the use of anaesthetic bagging. Unlike with an Ambu bag, which can use air, or oxygen entrained from a connected cylinder or oxygen concentrator, anaesthetic bagging introduces oxygen into the patient under pressure in order to recruit the lungs. The specialist PICU nurses act swiftly to avoid further desaturation when these episodes occur because Pippa has a noted tendency to desaturate rapidly. Even so, notwithstanding the exceptional nursing care on the PICU, on an average of about once a week Pippa has a more significant loss of oxygen when her level drops significantly below 80%. It has been known to fall to as low as 40% as happened on one day during the hearing. In such cases a respiratory physiotherapist may have to be summoned urgently to add to the efforts to bring Pippa’s oxygen levels back to an acceptable range. Again, specialist equipment such as the anaesthetic bag will be used.

42. Pippa receives excellent care on the Evelina PICU, but she is vulnerable to profound desaturations or some other complication that could take her life at any time. Predicting her life expectancy with continued long term ventilation on the PICU is difficult, but the balance of the evidence to me was that Pippa would live longer on the PICU than she would if on long term ventilation in a home setting, and whilst she could die at any time, she could live on the PICU for some years yet.

Trial of Portable Ventilation and Transition to Home Care

43. The notion that it might be possible to transfer Pippa home on long term ventilation first came from Dr Wallis. His proposal is supported, in general terms, by Dr Chatwin and Dr Playfor. This combination of expert voices, fully supported by Pippa’s mother, introduces an important consideration for the court – is it in Pippa’s best interests to embark on a process that might lead to her receiving long term ventilation and other life sustaining treatment at home? In order to answer that question, it is necessary to consider what the process of transition to home care would involve, and the prospects of that process succeeding.

44. The manner in which evidence about a trial of portable ventilation and transition to home care has been rolled out has not been very satisfactory. That is not a criticism of the legal representatives. I do however say that Dr Wallis ought to have recognised that his proposal of a trial and transition to home care would require considerably more detailed explanation than he had given prior to the hearing, particularly once he knew

that the treating team opposed it. For example, he gave very little further detail in his joint statement with Dr C, responding to some key questions merely by referring back to his first report. As a consequence, although Dr Chatwin had previously raised some issues about potential alterations to Pippa's regime, Dr Wallis gave a great deal of evidence about the process under questioning at the hearing, which he had not previously raised. Even in re-examination he introduced striking new evidence as to the nature of home care. This made it difficult for the Applicant to respond. When witnesses for the Trust were able to respond, their evidence, in turn, prompted further investigation by the Second Respondent, so that even after the hearing had concluded, a fourth report from Dr Chatwin was submitted. After representations by email I ruled against admission of Dr Chatwin's fourth report. It mainly concerned evidence of Pippa's oxygen saturation levels when not desaturating, and other aspects of her past respiratory management, and I do not find such further evidence to be necessary to my determination of the issues in this case.

45. Dr Wallis introduced the concept of a trial of home ventilation in his report of April 2020:

> "62. Home care may not be possible due to the high level of nursing and therapeutic input but this is currently not known with certainty. To explore the feasibility of this option, would require a tracheostomy and gastrostomy and the introduction of a package of management, tailored to Pippa's needs that can feasibly be provided by a team of home carers in a non-intensive care environment.
>
> 63. Although she is at the outer limits of possibility, living at home might be possible if shown that:
>
> a) A tracheostomy (possibly cuffed) provides a portal for ventilation, and airway clearance and bagging that is superior or equivalent to her current ETT;
>
> b) Her ventilatory needs can be provided by a home ventilator with the minimal of daily adjustments;
>
> c) Carers can achieve airway clearance and re-recruitment of lung if atelectasis occurs in the absence of regular physiotherapy input but with training in Pippa's care and physiotherapy needs;
>
> d) The family proceed with the discharge process aware that Pippa's high level of needs deems her vulnerable to complications that may lead to her death in the home environment despite her carers' best efforts.
>
> 64. It would be my suggestion that a tracheostomy should now be inserted and a package of care be trialled initially in the intensive care setting and, if successful, transferred to a step-down facility to determine whether home ventilation with current needs is feasible. It has to be recognised that there is an inherent risk to going home for Pippa but if the alternative is

> withdrawal of life-support, then this risk will have to be accepted by her therapeutic staff as well as mother. There is little to lose by exploring this option and is of no harm to the child."

Very helpfully, Dr Wallis has presented a flowchart demonstrating the steps towards home care. It is appended to this judgment at Appendix 1.

46. Dr Wallis has considerable experience at Great Ormond Street Hospital of transferring children from intensive care to a home setting. The same is true for the team at the Evelina. The Trust's witnesses responded with a number of concerns about this proposal but, whilst maintaining that the trial was not in Pippa's best interests, they produced a draft trial protocol which, in turn, received some criticism from Dr Wallis and Dr Playfor for being set up for failure. The thresholds for abandoning the trial were set too low in their opinion. In her oral evidence Dr A from the Evelina said she would be open to reviewing the protocol, the proposed ventilator settings, and the thresholds for abandoning the trial. Accordingly, the terms under which a trial would be carried out were explored in detail at the hearing. It is unnecessary for me to chart the course that this evidence took, but I shall set out what was established by the close of the evidence:

    a. The transition to home care is an iterative process involving a multi-disciplinary team working in conjunction with the family. There will be many obstacles and a positive approach to overcoming them is required if the goal is to be achieved.

    b. Every stage requires planning and risk assessment, but it has to be accepted that care at home will not be of the same clinical standard as care in the PICU. The care at home will not be optimal but it has to be "good enough". To embark on the process all have to agree that a lower standard of care is the price worth paying for the reward of caring for the child in a more nurturing environment, and one that suits the family.

    c. The first step would be to trial Pippa on a portable ventilator. She would remain in the PICU during this trial supported by the nurses and therapists who currently manage her, and all other equipment presently used.

    d. Although Dr Wallis initially maintained that it would be "pointless" to embark on the trial without first performing a tracheostomy, he relented at the hearing and said that the trial could be performed with the ETT still in situ.

    e. If, but only if, Pippa achieved stability during a two week period on a portable ventilator, which would include an absence of profound desaturations, she could then move to a non-PICU setting [to Box 8 in Appendix 1]. The initial trial stage might take more than two weeks if the view was taken that some of the settings on the ventilator could be altered, or other measures taken, to promote stability.

    f. If it had not already been performed, a tracheostomy would be performed soon after transfer to the transitional unit. At some stage thereafter Pippa would have to undergo a gastrostomy.

g. The non-PICU setting to which Pippa could be moved would still be within hospital and all equipment such as anaesthetic bagging and the cough assist machine, and therapies would be available. The next process is a lengthy one, lasting months. Pippa would remain on a portable ventilator barring any further setbacks. Step by step adjustments to her care would be made to replicate the care that would be available and needed at home. Plans for funding for her care, recruitment of a nursing team etc. could begin during this stage [Box 10, Appendix 1].

h. When home care has been replicated, and the home care package is assembled, Pippa would be ready to be transferred home [Box 11].

i. Although not mentioned in Box 11, were Pippa successfully transferred to home care, her life expectancy would be modest. She would be susceptible to complications including profound saturations that could not be as readily reversed in the community as they could in a PICU. When asked how long he would expect Pippa to survive if transferred to home care, Dr Playfor told me "many weeks …. some months".

47. Dr Wallis told me that the whole process of trial and transition would be likely to take at least six months. He said that overall there was a 1 in 4 chance of Pippa reaching the point of being discharged home with a full complex care package. However, if the initial trial were successful, he thought that there would then be about a 90% chance that Pippa would progress from the transition unit to home. As he told me, arrival at home is not the ultimate destination, it is the beginning of the next stage of her care. It would not be intended to discharge her home for palliative care, but to continue long term ventilation with a view to keeping her alive as long as possible. If, during the transition process, it became evident that home care was not achievable then the difficult discussion about withdrawal of ventilation would begin.

48. The treating team at the Applicant Trust does not believe that Pippa's condition warrants any attempt to transition her to home care. This is a process familiar to the team - the Trust has undertaken it with many other paediatric patients. Dr C told me that she is line manager for fifty patients who are ventilated in the community. Drs A and C and Ms F were perplexed at the suggestion that Pippa was at all suitable for home care. They have been looking after her for nearly two years in the PICU and with exceptional skill and high specification equipment have managed to keep her alive. Frankly, they believe there is no realistic chance that with less sophisticated equipment, and less specialist personnel, Pippa could survive more than a very short time at home. The treating team have stated that they would not be willing to perform a tracheostomy on Pippa for the purpose of the process Dr Wallis proposed and the Applicant seeks a declaration that it is not in Pippa's best interests to undergo a tracheostomy. It is not that the Trust is opposed to the use of tracheostomies for children on long term ventilation – nearly all such children in the Evelina PICU have undergone tracheostomies, and one was offered for Pippa in early 2019. Rather, their resistance to taking any steps towards a transfer home, in particular an invasive procedure such as a tracheostomy, is based on their belief that the exercise would be futile, and that the continuation of long term ventilation in any setting is contrary to Pippa's best interests.

49. The Trust's view is that Pippa's condition is such that she could not safely be cared for outside a PICU. The main reasons for that conviction are:

    a. Pippa needs a PICU ventilator which can be frequently adjusted as needed. A portable ventilator of the sort that would have to be used at home has a limited number of settings. Dr Wallis described to me how portable ventilators used by those of his patients who have been discharged home tend to have a "well" setting, a "sick" setting and perhaps one other setting for specific circumstances. In contrast the PICU ventilator can be operated with multiple adjustments during the day and night.

    b. As agreed by the respiratory physiotherapists Ms F and Dr Chatwin:
        i. An anaesthetic bag of the kind currently used to rescue Pippa when she desaturates cannot be used to administer oxygen in the community. Only an Ambu bag could be used, albeit with "entrained" oxygen rather than merely with air.
        ii. There are no community respiratory physicians in the area of Pippa's family home. In any event, even if there were, their role would only be to provide reviews of the care given. There would be no possibility of a respiratory physician visiting Pippa on a weekly or even monthly basis, let alone being on call in case of emergencies upon an episode of profound desaturation.
        iii. Saline lavage cannot be practised in the community – it is too risky.

    c. Proning would be potentially hazardous if practised in the community: if Pippa were to be cared for at home she would be ventilated through a tracheostomy. The advantage of such tubes is that they can easily be re-inserted, whereas an ETT requires re-insertion under general anaesthetic. However, when a child with a tracheostomy tube is in the prone position it is difficult to monitor whether the tube is still in situ. With Pippa's unpredictable head and neck movements, she could dislodge the tube without the disconnection being noted, with catastrophic results.

    d. Home care would involve a team of between 12 and 15 qualified nurses working in shifts and providing care 24 hours a day. Dr Wallis told me that half of the team could be health care assistants, but Dr Chatwin and the Trust's witnesses disagreed, advising that all staff would have to be qualified nurses. At least two nurses would be on duty at any one time. It would be very difficult to recruit such a team of nurses who could manage Pippa's respiratory condition.

    e. There is currently no funding in place for a sufficient package of home care, and no other Trust approached by the Applicant has yet agreed to undertake the transition process (the Trust itself being unwilling to perform a tracheostomy on Pippa, which would be an essential part of the transition).

50. All agreed that Pippa's life expectancy would be shorter if cared for at home than if she continued to receive long term ventilation and life sustaining treatment in the PICU. All agreed that there would be a risk of an unpredictable complication, such as a profound desaturation, which could prove fatal because of the limited resources available at home as compared with those in the PICU. Dr Playfor and Dr Wallis

emphasised that there are “ceilings of treatment” at home, and that families of children on ventilation at home, and the professional nursing team, have to accept the limits of provision and the consequent risks,. They have to be prepared for what to do as and when those risks materialise. As already noted, Dr Playfor considered that Pippa’s life expectancy at home would be “some months” only.

51. Amongst the new evidence introduced by Dr Wallis at the hearing, were the following:

    a. During re-examination Dr Wallis made a surprising claim that in a home setting Pippa could “go out for walks”. He meant that her portable ventilator could be positioned in a special wheelchair and she could be taken outside. He was the last witness to complete his evidence and there was no opportunity to explore this wholly new evidence with others. In particular, it was not clear to me what personnel and other equipment would have to be taken with Pippa in case she desaturated whilst outside. What is evident however, is that even at home Pippa would be permanently attached to a ventilator, she would require a tracheostomy and gastrostomy, and for most of the day, as now, she would be in a hospital bed, attended by nurses, undergoing suctioning and nurse led treatment and therapies.

    b. Further late evidence given by Dr Wallis during questioning was that failing home care, Pippa could be managed in some other form of community setting. The current position is that the relevant Clinical Commissioning Group has recently been made aware of Pippa’s case but has not begun to investigate it, let alone to offer funding. There has been no assessment of the suitability of Pippa’s family’s home for accommodating her, her equipment, and the necessary care team. Hence, I have no reassurance that her envisaged package of home care is practically achievable. Whilst appreciating that the CCG will not address Pippa’s needs and funding decisions until necessary, it does strike me as a gap in the evidence that no-one has made even a cursory assessment of the suitability of Pippa’s family home as a venue for her long term care. The Second Respondent’s case is focused on Pippa’s best interests being served by her being cared for at her home, not in some other community setting but I have no evidence that her home is suitable to accommodate her, her mother and brother, all the equipment needed, and a team of nurses who would need space and facilities of their own in order to function effectively.

    c. He also suggested, in passing, that even if Pippa could not reach Box 11 of his flow chart at Appendix 1 – care at home - it would be in her best interests to reach Box 8, namely care in a transition unit. This is not part of the Second Respondent’s case, no-one else suggested that the transition process was anything other than a means to an end, and Dr Wallis himself has said that in his view it would be contrary to Pippa’s best interests to continue to be ventilated on the PICU. With respect to him it is difficult to see why placing Pippa in a different part of the hospital would change that assessment.

    d. Dr Wallis politely suggested during his oral evidence that the treating team might think about certain adjustments to Pippa’s care, including the use of Glycopyrrolate and/or Scopolamine patches to reduce Pippa’s secretions, Botox injections of her salivary glands to reduce the production of saliva, surgical removal of the salivary glands, a change in ventilator settings so that Pippa was on a higher setting, and super-oxygenation. These adjustments might, he said, optimise the chances of a successful trial of portable ventilation and transition to home care. Witnesses at the Trust who subsequently gave oral evidence sought to address these suggestions. I was told that one of the leading specialists in salivary glands works at the Applicant Trust, had been consulted in the past about the option of Botox injections, and had ruled it out on the basis that it might well thicken her saliva and cause worse blockages. When told of that, Dr Wallis suggested that they might wish to think about it again.

52. I do not think it necessary or appropriate for me to make detailed findings as to whether the proposed adjustments should be made to how Pippa is cared for now or in the future, how the trial and transition process should be managed, or how the prospects of transition to home care could be optimised. It is not the court's function to give detailed directions as to a patient's medical management. On the other hand, it is necessary for me to form a view on all the evidence of the prospects of success in transferring Pippa to home care. Dr Wallis proposed that such a transition should be attempted, and I take full account of his experience and his evidence to the court. I accept that there may be several adjustments that could be made to optimise the chances of success of the trial and transition, but the trial and transition could only succeed if Pippa's current tendency to suffer intermittent profound desaturations ceased or was significantly reduced. In his first report Dr Wallis wrote at para. 54:

> "It is my opinion that Pippa's clinical condition is at the absolute outer limits of what might be achievable at home. It is rare that a child with complete absence of ventilatory drive, failure to cope with secretions, absent cough and susceptibility to aspiration and atelectasis has, in the absence of consciousness, been put forward for home care. In one instance in which I am aware that this was provided, it was with the understanding that the child would have a limited life quantity and that palliative care provided at home with LTV support package was in the family's best interests. Pippa would require 2 trained carers at all time who have demonstrated the ability to cope with her respiratory needs."

In oral evidence Dr Wallis confirmed that that child, unlike Pippa, had some awareness of their environment. Dr Wallis knew of only two children with similar neurological conditions to Pippa's who had been transferred to home care, but they did not have the same severe respiratory problems that she has. When pressed during his oral evidence, Dr Wallis assessed the prospects of a successful trial of portable ventilation as being between 30% to 40%, and the overall chance that the trial and transition process would succeed in allowing Pippa to receive long term ventilation at home as being about 25%.

53. Dr Chatwin also thought it less than probable that Pippa would be able to transition to home care. Dr Playfor said that that there was a greater than 50% chance of portable ventilation being viable but did not express a view as to the overall chances of a transition to home care being completed. The weight of these experts' opinion evidence was that it is possible but unlikely that Pippa's management could be negotiated through

transition to home care. These experts did however acknowledge that their evidence was based on the notes, their experience of other patients, and relatively brief interactions with Pippa herself, whereas the Trust's witnesses had much more extensive experience of treating Pippa. Ms F for example told me that she had had direct dealings with Pippa on some 75 occasions. She has considerable hands-on experience of managing her desaturations. The Trust's clinicians are adamant that there is no realistic chance of Pippa transitioning to home care. A distinctive difference in attitude to transition emerged during the hearing. The Second Respondent's experts were more inclined to accept risk, to acknowledge that care at home could not and need not be optimal – it only had to be "good enough". If the alternative is withdrawal of ventilation in the PICU and death, then, they contended, it is worth taking the chance that transition to home care might work even if the chance is as low as 25%. In contrast the treating clinicians were adverse to giving Pippa less than optimal care and concerned that the proposed process was based on wishful thinking rather than the reality of Pippa's unstable respiratory condition.

54. I take into account the fact that the Second Respondent's expert witnesses might be able to form a more independent overview than those clinicians responsible for Pippa's ongoing care who were particularly anxious to keep up the very high standards of care they have offered to Pippa to date. Nevertheless, in my judgment Dr Wallis' assessment of a 25% chance of Pippa being successfully transferred to long term ventilation at home is too optimistic. It cannot easily be reconciled with his initial view that Pippa's condition was at the "absolute outer limits" of what can be managed at home. It is agreed that care of Pippa at the Evelina has been exceptional. She has had only a handful of respiratory infections during nearly two years on the PICU. Considerable thought, effort, and resources have been put into managing her complex respiratory problems. Even so, she has suffered numerous profound desaturations, and would have suffered more had her desaturations not been intensively and expertly managed. Against that background it is difficult to see how transfer to a less sophisticated ventilator and the removal of some of the interventions that have so far protected Pippa, could realistically alleviate her respiratory problems or lead to fewer or less profound desaturations, even with adjustments to her management. I give weight to the direct knowledge of managing Pippa that the Trust's witnesses have and which informs their pessimism about the prospects of a trial and transition to home care. I also take into account the chances of a fatal complication occurring during the transition period, and the practical difficulties in setting up a care regime at home. Weighing all the evidence I have read and heard, I am satisfied that the chances of Pippa being able to be transferred to long term ventilation at home are remote. There is only a remote possibility of the trial and transition succeeding such that she could be discharged home. It is more likely than not that the failure of the process would be known at an early stage, perhaps even within the first two weeks, but just as it cannot be known with certainty that the process would fail, it cannot be known in advance when any failure would occur.

The Views of Pippa's Family

55. No-one is closer to Pippa than her mother. She knows what Pippa was like as a child before ANE struck, and she has stayed beside her daughter throughout her time on the

PICU. Parental views do not determine what is in a child's best interests, otherwise there would be no role for the court in a case such as this, but they have significant value, as I shall consider more fully when conducting my assessment of Pippa's best interests. Albeit with some hesitation, given that I have no statements or other evidence from other members of Pippa's family, I proceed on the basis that Ms Parfitt speaks not only for herself but for the family as a whole.

56. Ms Parfitt's view, clearly expressed in her oral evidence, is that it is in Pippa's best interests to continue to receive life sustaining treatment because:

    a. It is "God's law" – by which I understand her to mean that there is a duty to preserve Pippa's God-given life. I received no other evidence to suggest that Ms Parfitt or her family actively practise within any faith, or hold other strong ethical views based on religious or secular teaching or values.

    b. Some patients recover from severe brain injury. Pippa made progress after her first episode of ANE, and she has made some recovery since January 2019. She has the basis from which further recovery could be made.

    c. The home environment and her mother's care are the contexts most likely to allow Pippa to achieve further recovery.

    d. Keeping Pippa alive would allow her to enjoy the benefits of any developments in medical science.

    e. Pippa will benefit from being in the warm embrace of her family in a familiar home. Her brother would return home – he is currently looked after by relatives in their own home - and Pippa would be reunited with him.

57. These views require some scrutiny. I accept without hesitation that the preservation of Pippa's life should be given considerable weight. As to Pippa's progress and level of functioning, Ms Parfitt says that Pippa has improved since January 2019, even after surviving the initial crisis. She says that Pippa was initially very static but began to move her fingers and then her whole limbs. In her second statement dated 3 November 2020, she says,

> "I believe Pippa has made good physical and cognitive progress in the 21 months since her initial arrival at the Evelina at a slow pace and continues to improve day by day. I believe my daughter has retained sufficient cognitive functioning that there is a base to build some form of cognitive recovery. I base this opinion on my unique intricate maternal knowledge of my daughter and the extent to which she is presently responding which I see daily."

On visiting Pippa in the PICU, I noticed that she was wearing her own, bright clothes and that her hair had been plaited. Her eyes were open and she moved her left arm up and down. She was surrounded by her soft toys. She has no dysmorphic features and normal head circumference. The Professor of Paediatric Neurology from

Addenbrooke's Hospital who was asked to give a second opinion in May 2019, advised that Pippa had suffered such severe brain damage that future treatment would be "considered futile", but "looking at Pippa I can entirely understand why any parent would find that hard to understand as she looks so normal in so many ways."

As for changes in Pippa's movements over time, Dr Playfor, on whose evidence the Second Respondent relies, says,

> "The pattern of Pippa's movements has changed since January 2019; initially she was described as being floppy and largely motionless but has gradually developed increasing, quite vigorous spontaneous movements. In my opinion this change represents the neurological evolution and maturation of the underlying brain injury rather than any form of improvement in her condition. I have seen no evidence to suggest that Pippa performs any purposeful movements."

58. Ms Parfitt's view is that Pippa will make further recovery if she is cared for at home, but none of the medical witnesses believe it likely that Pippa will make any form of recovery. Ms Parfitt's view is that at home Pippa would benefit from her mother's care such as being fed, but the undisputed medical evidence is that if Pippa were to go home she would require a gastrostomy to allow her to be tube fed. I have viewed twelve videos of Pippa submitted by Ms Parfitt. One has been given the title, "Pippa looking around the room", but the agreed neurological evidence is that Pippa has cortical blindness – her eyes roll but she cannot see. The videos show Pippa as I found her on my visit. The overwhelming weight of expert evidence is that Pippa has no awareness of her environment, that she has not regained any neurological function since January 2019, and that she will not do so in the future. Ms Parfitt's views on Pippa's best interests are based on her faith and determination that by committing herself to her care, she can help her daughter to enjoy some recovery. That is at odds with all the other evidence in this case, including the expert evidence on which she relies.

59. As to the general prospect of medical advances being made that would advantage Pippa in the future, it is clear to me that no court could sanction giving a child life-sustaining treatment merely because there might be some medical breakthrough from which they could benefit at some indefinable point in the future. That would clearly be the case where the child was suffering pain or discomfort due to ongoing treatment, but it is no less so in a case where the child does not experience pain.

60. The final benefit claimed for the provision of life-sustaining treatment at home, is that Pippa's welfare would be advanced by her being within the bosom of her family and in her own home. Even if Pippa had significantly less brain damage than she does, she might well not be able to remember her home, where she has not been for the last two years of her short life. As it is, her brain injury is much too severe to expect her even to be aware that she is in her family home. However, the key benefit being relied upon is not the house itself, but that Pippa would be living with her family. Pippa's brother would return home and so she would be living under the same roof as him as well as

with her mother and, I was told, the family dog. Other members of the family would be able to come and go from the home, rather than visiting Pippa in hospital.

The Views of the Medical Professionals on Pippa's Best Interests

61. The Trust relies on evidence from the clinicians who lead Pippa's treating team. The second respondent cannot do that and she has instructed independent experts. Expert medical evidence is permitted when it is necessary to help the court to determine the issues in a case. The medical expertise of Dr Playfor, Dr Wallis, Dr Chatwin, and others is of great assistance to this court, and their evidence on medical matters carries considerable weight, as does the evidence of the Trust's clinicians, all of whom also have considerable experience in treating extremely unwell children. It is well established that the court should take account of the views of a child's treating clinicians when assessing best interests, but how should the court treat the views of those clinicians, and of the independent medical experts, on the non-medical aspects of a child's best interests? Dr Playfor and Dr Wallis in particular expressed views on Pippa's best interests that went well beyond medical matters. Their views are relied upon by the Second Respondent and I address them in detail later in this judgment. In my view their opinions, and those of the treating clinicians on all matters touching on Pippa's best interests, are welcome because their experience in caring for very ill children gives them considerable insight into how children deal with adversity, how even very disabled children interact with their families, and what a child is like when at the very edge of life. In addition to their experience of such children generally, Pippa's treating clinicians have specific knowledge of Pippa, and have seen her with her mother and other members of her family. The views of all the medical witnesses on the non-medical aspects of best interests carry less weight than their views on medical matters, but I do take them into account.

62. Dr A and Dr Playfor agree that continued ventilatory support in the PICU is not in Pippa's best interests. This was also the view of the independent intensivist from Cambridge from whom the Applicant Trust obtained a second opinion in September 2019. Dr A's view that long term ventilation should be withdrawn is, she told me, shared by all of the 14 consultant intensivists working at the PICU at the Evelina Children's Hospital, and is a view which none of the 150 nurses on the unit have opposed, nearly all having been given the opportunity to do so. In contrast, Dr Playfor considers that it is in Pippa's best interests to continue with life sustaining treatment "in order to allow the steps identified at paragraphs 63 and 64 of Dr Wallis' report to be implemented, to ascertain the feasibility of a discharge home, pending a decision on it by the court." In his first report he wrote:

> "There is no doubt that Pippa's case arguably fulfils the criteria described the RCPCH where withdrawal of LST [life sustaining treatment] can be considered, specifically that the severity of her condition is such that it is difficult or impossible for her to derive benefit from continued life. Pippa's brain injury is so severe that there is no evidence that she is experiencing pain, but equally no objective evidence that she enjoys pleasurable experiences in her

> daily life. It is my opinion, by the finest of margins, that withdrawal of LST is not in Pippa's best interests."

In oral evidence he clarified, without hesitation, that in his view it would not be in Pippa's best interests to continue life sustaining treatment within a PICU setting, and that it would be in her best interests to withdraw life support if there were no other feasible option than continued ventilation on the PICU. For him, there is a material difference between prolonging life on the PICU and attempting to get Pippa home so that life can be prolonged there. To be clear, he did not contend that Pippa's best interests were to be sent home with a view to withdrawing treatment, but rather that it was in her best interests to attempt a trial of portable ventilation with a view to her being sent home to be ventilated and given life sustaining treatment.

63. Dr B and Dr Spinty, the two expert paediatric neurologists from whom I have received written evidence agree that it is not in Pippa's best interests to continue with life-sustaining treatment and that it is in her best interests to withdraw such treatment. That was also the view of the consultant paediatric neurologist at Addenbrooke's Hospital, Cambridge, who was asked to give a second opinion by the Trust in May 2019.

64. Dr C shares the view of the intensivists at the Trust that continued ventilation is not in Pippa's best interests. She is extremely sceptical about the feasibility of home care, and unconvinced that it would be safe for Pippa to be cared for at home, because her respiratory care needs can only safely be met on a PICU. Her respiratory needs are too complex even to be managed on a High Dependency Unit, let alone in the community. She does not think it in Pippa's best interests to be removed from the PICU setting for the purpose of providing long term ventilation elsewhere. The PICU is where she can be given optimal care. Dr Wallis encapsulated his view on best interests in two paragraphs of his first report:

> "60. Continued support in an intensive care environment is not a long-term viable option for Pippa and would not be in her best interests.
>
> 61. Ongoing support in her home environment surrounded by family and carers would give her the [chance] of an improvement in her life quality as well as enhancing the mutual life experiences with her wider family who continue to provide devotion and love."

Under questioning, Dr Wallis accepted that there would be no mutuality involving Pippa because she would not be aware of any life experiences. The "mutual life experiences" would be enjoyed by the wider family, not her. He also told the court that Pippa is capable of "giving and receiving love". Clearly, Pippa cannot communicate and she cannot reach out to touch in any purposeful way – she has no conscious awareness of her environment and she can derive no pleasure from life. I understand Dr Wallis to mean that Pippa is the focus of love, which is manifestly true whether she is kept alive on the PICU, in a transitional unit, or at home.

65. When asked at court, Dr Chatwin was reluctant to give her view on Pippa’s best interests but supported the idea of a trial of portable ventilation. Ms F regarded the question of Pippa’s best interests as outside the scope of her expertise. The physiotherapy and occupational therapy witnesses also chose not to express views on Pippa’s best interests.

66. Notwithstanding their differing views as to Pippa’s best interests, there was clearly considerable mutual respect amongst the medical professionals, and I understood them all to accept that each other’s views on the question of best interests were within a reasonable range of opinion, albeit it appeared to me that some of Pippa’s treating clinicians said so with significant reservation.

Pippa’s Ascertainable Wishes, Feelings, Values and Beliefs

67. Pippa was 20 months old when she suffered the first episode of ANE. This left her significantly disabled and with cognitive impairment, but she was able to undergo rehabilitation and to be discharged home into the care of her mother. She remained at home for about eighteen months until ANE struck again, leaving her in a PVS. She was then 3 years, 8 months old. It is not possible to ascertain her current wishes and feelings. She is not “locked in” and she is almost certainly incapable of forming conscious wishes, let alone having any thoughts about her continued treatment. I take into account that before she lost her capacity for conscious awareness, Pippa knew that she had the unconditional love and dedication of her mother, her brother, and the rest of the family. She made progress at home in their care after the first episode of ANE. This showed that she responded positively to being cared for at home.

68. The evidence of Ms Parfitt does not assist the court in determining what Pippa’s views about continued treatment would have been had they been capable of being ascertained. There can be little doubt that any young child who is loved and well cared for, would want to be at home with their family rather than in a hospital. However, it is not possible to know what Pippa’s wishes and feelings would be in relation to the continuation of long term ventilation and other life sustaining treatment needed to allow her to attempt a transition to home care. Nor is it possible to impute to her any particular ethical, religious, or other values and beliefs. I would hesitate to do so for any five year old, let alone in Pippa’s own case.

The Views of the Guardian

69. Ms Doyle is appointed to act on behalf of Pippa. She has produced two reports to the court. In the first, dated 27 October 2020, Ms Doyle supported a trial of portable ventilation taking place but with the significant caveat that she had not yet seen all the medical evidence relating to such a trial. In her second report dated 2 December 2020, having reviewed all the medical and other evidence then available, Ms Doyle concluded:

> "It is with great regret that having carefully considered Pippa's unique needs and individual circumstances I have come to the conclusion that it is not in Pippa's best interest to undergo the protocolised ventilator approach trial. Also, I cannot see how it accords with her best interest to continue receiving life-sustaining intervention. I recognise that the assessment which I have formed in this report will deeply upset her mother, brother, grandparents, and extended family members and if this is the decision of the court it will be difficult to accept.
>
> Having regard to Pippa's life experiences and considering Section 1 of the Children Act 1989, The Welfare Checklist, I do not find it in her best interest to receive treatment that is harmful or that is unable to meet her specialist needs. When thinking about the definition of harm, to mean 'ill treatment or the impairment of health or development', I find that a care environment outside of the PICU has now been established as unsuitable to care for Pippa's long standing, serious and life-threatening illness. Pippa cannot tell us about her experience of life, but it is evident that due to the most severe and debilitating of health conditions her day to day life is characterised by repeated life sustaining intervention and medical care. A final determination is now needed on whether it remains in her best interest for her life to be supported within the PICU."

On behalf of the Guardian, Mr Davy confirms in his closing submissions that she remains of the view that the court should make the declarations sought by the Applicant Trust.

Pippa's Best Interests

Continuation of Long Term Ventilation on the PICU

70. Fundamental to the Second Respondent's case is that it is in Pippa's best interests to be cared for at home rather than in the PICU. There is unanimity amongst the independent medical experts and treating clinicians that it is not in her best interests to be given long term ventilation in the PICU. Although Ms Parfitt would prefer that outcome if the only alternative were withdrawal of ventilation, her Counsel do not submit that long term ventilation on the PICU is in Pippa's best interests. Nevertheless, for reasons already given, it is necessary in my judgement first to consider what I have described as Option A – whether it is in Pippa's best interests to continue with long term ventilation on the PICU. A comparison can then be made with long term ventilation at home, which will help to determine whether steps should be taken to embark on a process that might lead to long term ventilation at home.

71. I give considerable weight to the preservation of life. Ms Parfitt also firmly believes in the principle that life should be preserved: she told me that it was "God's law". In the case of a child, the presumption that life should be preserved reflects common values

that children's lives should be protected and nurtured. This is an important factor weighing in favour of continuing the long term ventilation and other treatment that Pippa requires to keep her alive. However, there is, in law, no rule that life must be preserved in all circumstances and at whatever cost to the child. The presumption that life should be preserved is not a determinative factor and must be considered together with other factors relevant to Pippa's welfare and best interests.

72. The medical evidence overwhelmingly supports the conclusion that Pippa is in a persistent vegetative state with no prospect of improvement with time or with treatment. Pippa's disabilities are as grave as can be imagined. I have set them out earlier in this judgment, but, in short, she cannot see, breathe, or communicate, she has no awareness of her environment or of interactions with others, she has no purposeful movement, she is unresponsive to visual, auditory or tactile stimulation, she is doubly incontinent and she has to receive interventions throughout the day and night to prevent potentially fatal oxygen desaturations.

73. It is very rare for a child of her age to have been maintained in her current state for nearly two years in a PICU. The fact that she has not shown any sign of neurological improvement during that period leaves no reasonable doubt that she will remain in her current condition for as long as she lives. There is no hope of future improvement. Ms Parfitt's evidence stands alone in suggesting both that Pippa has shown some signs of progress to date, and that she will improve in the future. Ms Parfitt's care for Pippa after her first episode of ANE helped Pippa to improve and, as she told me, some patients may recover from brain injuries against medical expectations, but there is no evidence before me on which I could find that to be possible, let alone likely, now in Pippa's case. The suggested adjustments to her respiratory management would not be of any benefit to Pippa were she to remain on the PICU. I am bound to conclude, on the basis of the very clear medical evidence, that the second episode of ANE has left Pippa far more disabled than her first, and that she is in a PVS from which she will not enjoy any form of recovery.

74. Ms Parfitt spends about sixteen hours a day with Pippa. Her dedication to Pippa has moved and inspired members of her own family, staff at the Evelina, and many others. Very sadly however, the exceptional support from her loving family and the skilled and dedicated staff at the Evelina has not, and will not, confer any benefit to Pippa of which she can be aware. There is no subjective benefit to Pippa from being kept alive on the PICU.

75. On the other hand, Pippa cannot feel any pain, and this absence of awareness of pain is a critical aspect of the Second Respondent's case. Dr Wallis said, in relation to attempting transition to home care, that "there is little to lose by exploring this option and [it] is of no harm to the child". In their opening position statement, Counsel for Ms Parfitt contended that "by definition there is no physical harm caused by the provision of medical treatment to a person with no conscious awareness." If Pippa cannot suffer pain, should the court take into account her ongoing condition and treatment as disbenefits in the assessment of her welfare and her best interests?

76. I do not accept the Second Respondent's Counsels' submission that no physical harm can be caused by medical treatment to a person with no capacity to feel pain and no conscious awareness. Physical interventions to prolong life should not be regarded as

irrelevant to the consideration of welfare, just because the patient has no conscious awareness and cannot experience pain. Any proper assessment of welfare in a case involving life sustaining treatment ought to take into account the nature and extent of the interventions necessary to keep the patient alive. Clearly much greater weight should be given to the harm caused by those interventions if the patient can feel pain or discomfort. If Pippa were able to experience pain and discomfort when undergoing the multiple invasive procedures she undergoes each day, that would be highly material to the assessment of her welfare. But her loss of conscious awareness does not mean that those interventions can now be wholly disregarded. In Pippa's own case she not only requires artificial ventilation, nutrition, and hydration, but, day and night, she requires other interventions including suctioning, bagging, proning, and use of the cough assist machine, as well as other less frequent interventions such as saline lavage. Both her ongoing condition and her necessary treatments in the PICU constitute burdens upon her person notwithstanding her lack of conscious awareness. In any event, the absence of pain is not the same as the absence of harm. The fact that a person has no conscious awareness does not give their clinicians, or anyone else, licence to perform procedures on them irrespective of their benefit. Compensation payments for "loss of amenity" have been made to patients who are in a coma because the law recognises that even the fully unconscious individual may experience a loss of function and a diminished quality of life even if they do not suffer pain – *Wise v. Kaye* [1962] 1 Q.B.638 and *H. West & Sons Ltd. v. Shephard* [1964] A.C.326, applied in *Lim Poh Choo v Camden & Islington Area Health Authority* [1980] AC 174. The losses of freedom, function, and ability to enjoy childhood, that severe disability, including severe brain damage, cause someone such as Pippa, are a form of harm which should be considered in assessing her welfare, whether or not they can feel pain and whether or not they have any conscious awareness.

77. Accordingly, it would be an error to allow the absence of pain, or of any sensation, to prevent a wider consideration of welfare incorporating a consideration of physical and other harm or detriment to Pippa, from her condition, and from the treatments she needs to keep her alive. In Re *A (A Child)* [2016] EWCA Civ 759, King LJ concluded at [57]:

> "In the present case almost the entirety of the oral evidence and a substantial part of the judgment related to the issue of 'pain'. Although it is undoubtedly the case that a single factor can be of such overwhelming importance as to be determinative (for example where a child is in significant and unmanageable pain or distress) the emphasis here focused disproportionately on one item which, although relevant, did not in reality go to the heart of the decision. As a consequence, there was a real danger, repeated again before us, of a failure to stand back and consider A's welfare in its widest sense."

And at [58] King LJ approved the approach taken by Parker J,

> "… even if his life were completely pain free, I would come to the conclusion that there is no measurable benefit to him to continue in his present condition and it is simply inhumane to permit it to continue. It is not in his best interest to continue treatment other than palliative care, and it is in his best interests for all other treatment to be withdrawn."

78. In the light of these considerations, I do take into account the detriment to Pippa's welfare caused by her condition and the treatment for it, even though she is unaware of that detriment. She is a five year old girl who has lost virtually all her functioning. She is constantly subject to invasions of her person to keep her alive. It is insufficient to view her condition as depriving her of benefit. Her condition and the treatment it necessitates are significant burdens. Even if one discounted these factors in the welfare assessment, on the grounds that Pippa has no conscious awareness of them, they ought to be taken into account in the broad assessment of her interests. It must be relevant to any assessment of her interests that she has such grave loss of function and requires such intensive and intrusive treatment to preserve her life.

79. Pippa cannot derive any pleasure from life because she has no conscious awareness. Are there nevertheless other benefits to her, from the prolongation of her life, such as preserving her dignity, or allowing her to remain the focus of the love of her family, that the court should take into account? Or, if those are not benefits to her welfare, are they matters that should nevertheless be considered when assessing her best interests? The Second Respondent relies heavily on the decision of MacDonald J in *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), in particular [168] to [177] and [186]. At [172] MacDonald J said,

> "Tafida is more than simply a patient who is the subject of medical treatment. Within this context, the benefits of life-sustaining treatment may extend beyond the merely medical. If the argument in *Bland* that Anthony Bland felt no pain or awareness and therefore had no interests which suffered from his being kept alive is demonstrated to be a fallacy because, in the words of Hoffman LJ (as he then was), "it assumes that we have no interests except in those things of which we have conscious experience", then the argument that a child who feels no pain and no or minimal awareness can derive no benefit from being kept alive is similarly fallacious in circumstances where, again to echo the words of Hoffman LJ, the foregoing assumption does not accord with many people's intuitive feelings about their lives, and particularly those people who have a strong religious faith."

At [176] to [177] he said,

> "[176] I have also paid careful regard to the Trust's submission that even if Tafida feels no pain, further invasive treatment over an extended period of time will impose an unacceptable burden on her human dignity, which burden will be increased as she develops further debilitating physical symptoms. Again, I accept that within the context of the frame of reference advanced by the Trust, namely continued invasive medical treatment over many years with little recuperative benefit may, for example in the manner articulated in Bland, reach the point of indignity for Tafida. The concept of human dignity as an element of the best interests analysis is however, not without difficulty. The term 'human dignity' does not lend itself to precise definition and

> there is no universal agreement as to its meaning. The concept of human dignity must, accordingly, contain a significant element of subjectivity and thus be influenced by, for example, the religious or cultural context in which the question is being considered. In *M v N* (2015) 148 BMLR 116, [2016] COPLR 88 (at [72]) Hayden J observed that:
>
> 'There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain. There will undoubtedly be people who, for religious or cultural reasons or merely because it accords with the behavioural code by which they have lived their life, prefer to, or think it morally right to, hold fast to life no matter how poor its quality or vestigial its nature. Their choice must be respected. But choice, where rational, informed and un-coerced, is the essence of autonomy. It follows that those who would not wish to live in this way must have their views respected too.'
>
> [177] … the question of whether continued treatment would burden Tafida [Raqeeb] with indignity falls to be considered, once again, in the context of the agreed evidence that, ultimately, whilst moribund, with minimal awareness and entirely dependent on the care of others, it will be possible for Tafida to be cared for at home by a loving and dedicated family and consistent with the religious code and community values within which she had been raised. In the context of the concept of human dignity, although difficult to define, I am satisfied that this is a significantly different proposition to, for example, continued care over a period of years confined in a Tier 2 ICU unit."

80. I am currently considering whether continued ventilation in the PICU is in Pippa's best interests. Although MacDonald J found that dignity and receiving loving care in a home setting, rather than in the ICU, were benefits or factors that promoted the interests of the child, the fact is that he found such benefits or interests could exist. Dr Playfor has been involved in a number of cases involving decisions about life sustaining treatment for children, including *Raqeeb*, in which he gave evidence that continued ventilation would not be in the child's best interests. He told me that the *Raqeeb* judgment had changed his mind in relation to these extremely rare cases. I commend him for being open-minded, and for his frankness in accepting that his evidence in the present case is inconsistent with his evidence in *Raqeeb*, not because he relied on any particular difference on the facts, but because he has thought again, read around the subject, and come to a different view. In his written evidence he referred to the same passage from Hayden J's judgment in *M v N* that MacDonald J quoted at para. [176] of *Raqeeb*. He then observed, echoing MacDonald J's words at [169],

> "although severely disabled, with no demonstrable awareness of the environment and entirely dependent on the care of others, Pippa's life has inherent value; it is nurtured and precious to her mother, sibling and wider family. Pippa's existence can be said

> to add, admittedly in a modest manner, to the body of collective human experience.”

81. I would respectfully agree with Dr Playfor except that I would replace the word “modest”. With “significant”. A child such as Pippa can contribute significantly to the lives of others and to the body of collective human experience. She is an exceptional child who has inspired exceptional behaviour from others: the selfless devotion of her mother, the sacrifices of her brother, the loving support of other family members, the dedication and skill of the PICU doctors, nurses, and therapists. Many people will have learned from Pippa’s life and experiences: doctors, nurses, therapists, and other parents whose children have passed through the PICU at the Evelina.

82. I do, however, have difficulty in accepting Dr Playfor’s analysis, not least because MacDonald J found that although it was likely that Tafida Raqeeb could not perceive pain in her resting or standard state [162], she had “retained a minimal level of awareness” [161]. As MacDonald J said, in medical cases like Pippa’s and Tafida Raqeeb’s, where there can be no absolute certainty as to their subjective experience, it is important to maintain fidelity to the standard of proof, particularly when the decisions for the court are so grave [175]. Applying the standard of proof, this court must assess Pippa’s best interests on the basis that she has no conscious awareness, whereas MacDonald J assessed Tafida Raqeeb’s best interests on the basis that she retained minimal awareness. In the present case there is a high degree of probability that Pippa has no conscious awareness. This distinction affects consideration of the benefits to Pippa of human interaction and loving care from the family.

83. Furthermore, the points that Dr Playfor makes would seem to me to apply even whilst Pippa is being kept alive on the PICU. Surely the “inherent value” of her life does not depend on whether she is cared for in a bed in a hospital or at home? Yet Dr Playfor does not believe it is in Pippa’s best interests to be kept alive on the PICU.

84. Insofar as a plea to respect the “inherent value of life” or to the “innate dignity of life” directs the court’s attention to the presumption that life should be preserved, it is uncontroversial. The law recognises the inherent value of Pippa’s life by giving considerable weight to its preservation, but the fact that life has inherent value is not determinative of the best interests assessment. Lord Donaldson of Lymington said in *Re J (A minor) (Wardship: Medical Treatment)* [1991] Fam 33 at page 46:

> "There is without doubt a very strong presumption in favour of a course of action which will prolong life, but … it is not irrebuttable … Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment… We know that the instinct and desire for survival is very strong … 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."

85. Insofar as Dr Playfor's view is that the value of Pippa's life can be seen in what she can bring to others, I am afraid that I do not accept that I should take that into account in an assessment of her welfare or her best interests. Her life does have worth and value which can be seen most clearly in what it brings to others, but the assessment of best interests has to be made from the point of view of the child. Pippa's condition renders her unaware of the benefits she brings to others. Not only is her welfare my paramount consideration, but it would be wrong, in my judgment, to take into account the welfare of others when determining her best interests.

86. The concept of "dignity" to which MacDonald J referred in *Raqeeb* at [176] to [177] (above) and which has influenced the view of Dr Playfor, is, I believe, problematic and does not assist me in identifying what is in Pippa's best interests. In an adult or older child the concept of dignity might be linked to their exercise of autonomy and be a crucial factor in determining what is in their best interests, but that factor does not apply in the case of a young child like Pippa, whose values, beliefs, and wishes cannot reliably be ascertained or inferred. Perhaps we all think we can recognise human dignity when we see it, but there is obviously a high degree of subjectivity involved in describing someone's life or death as having dignity. The protection of an individual's dignity has been deployed in support of decisions to continue life sustaining treatment – *Raqeeb* – and to withhold it - *Alder Hey Children's Foundation Trust v Evans* [2018] EWHC 308 (Fam) at [62]. For some, there is dignity in enduring suffering; for others, prolonged suffering constitutes a loss of dignity. There is a wide range of opinion as to what constitutes a dignified death. In the present case the Trust contends that the withdrawal of ventilation in a planned manner within the hospital and with appropriate palliative care, would allow Pippa to die peacefully with her family around her. Witnesses for the Trust told me of "chaotic" deaths they had witnessed, and which might occur if Pippa were at home, where a complication such as an uncontrollable desaturation could lead to her sudden death, perhaps without family members present. It might be said that Pippa's dignity would be protected in the former case and lost in the latter. Her mother would strongly disagree. She says, "I could not think of anything more undignified than Pippa's death being planned and for it to be carried out in the corner of the PICU when there is a procedure that can be done to potentially get her out of the ward and home." I take into account the views of Pippa's mother and of others about her best interests, but given the very different ideas expressed to the court about what would constitute dignity for Pippa in life and in her dying, I shall not presume to adopt some supposedly objective concept of dignity to determine her best interests.

87. I have already noted the important difference in level of awareness between Tafida Raqeeb and Pippa. There are other material differences. Pippa has spent nearly two years on ventilation in the PICU whereas Tafida had had seven months of ventilation prior to the hearing. This is not a small difference – MacDonald J placed some reliance at [176] on the impact of more prolonged ventilation and intensive care on best interests. There was no suggestion that Tafida Raqeeb was vulnerable to the multiple life threatening desaturations that Pippa suffers, requiring specialist assistance. There was a "fully thought out and funded care plan" to move Tafida to be cared for by her family at home on a ventilator and all the experts agreed that Tafida could be ventilated at home, whereas it is currently unknown whether home care is feasible for Pippa: Tafida's was "not a case where transport of the child remains simply a theoretical option…." [179f]. The court in *Raqeeb* heard "on the Trust's own evidence" that the proposal for home care was "consistent with the domestic approach in other areas to

children in a similar position to Tafida." In the present case no-one has experience of someone with Pippa's particular constellation of problems and needs being cared for at home.

88. So, what is the "impalpable factor" or other benefit that continuation of life will bring to Pippa beyond the prolongation of life itself, beyond the advantages or comfort it might bring to others, and beyond the subjective and malleable concept of dignity? Dr Wallis and Dr Playfor cannot find any benefit in continued care in the PICU, even though Pippa would continue to be the focus of the unconditional love of her mother and wider family, and to receive exceptional family, medical and nursing care. Counsel for Ms Parfitt do not point to any such benefits in their submissions. Likewise, I cannot find any palpable or impalpable benefit to Pippa from prolonging her life in the PICU. Is it inconsistent to find that a young child with no conscious awareness suffers burdens but enjoys no benefits from the prolongation of life? I do not believe so. The profound loss of function and the daily invasion of her bodily integrity necessary to prolong her life constitute objectively identifiable burdens on Pippa's person. Factors that might constitute some kind of benefit to an adult or young person, such as affirmation of deeply held values, or respect for autonomy, do not apply to a very young child such as Pippa.

89. I take into account the views of Pippa's family as to whether continued ventilation on the PICU is in Pippa's best interests, and the contrasting views of the treating team, the independent experts, and Pippa's guardian. As for Ms Parfitt, she wants Pippa to be kept alive, but has no wish for her to be kept on the PICU. I shall discuss the relevance of parental wishes in more detail in the context of the possibility of home care, but, following the ECtHR judgment in *Gard and Others v UK* (above), I do take into account Ms Parfitt's wishes in my assessment of Pippa's best interests. In any event Ms Parfitt does have an Art 8 right to a family life to which I have regard.

90. Considering the evidence as a whole and balancing all the relevant factors, I am satisfied that it is not in Pippa's best interests to continue to receive long term ventilation or other life sustaining treatment on the PICU. I have to consider Pippa's best interests from her perspective. Notwithstanding the presumption that life should be preserved, it is not in her best interests that her life should be prolonged. Her welfare is my paramount concern. Pippa is in a persistent vegetative state and has been for well over a year. She has no conscious awareness and she gains no benefit from life but she daily bears the dual burdens of her profoundly disabling condition and the intensive treatment she requires to prevent it from ending her life. The evidence drives me to conclude that Pippa has no awareness of her environment nor of interaction with others, including, I am very sorry to say, her family. She receives exceptional care from her mother, others in her family, and from the healthcare professionals at the Evelina, but as all the medical witnesses have advised the court, there is no hope of improvement in her condition and no medical benefit from prolonging her life on the PICU. I cannot identify any non-medical benefits to Pippa from continued ventilation on the PICU, whether social, emotional, psychological, or otherwise. Prolonging her life on the PICU will only prolong her burdens. Continued care on the PICU is not the primary wish of her family, although they would prefer her to live rather than to have ventilation withdrawn. I take into account their wishes and views. I also take into account the view of the treating team and the independent experts. Ultimately, however, the court has to take an objective view of Pippa's best interests. Taking a broad view of Pippa's medical

and non-medical interests, but with her welfare as the paramount consideration, I conclude that it is not in her best interests to continue to receive mechanical ventilation on the PICU.

Embarking on a Trial of Home Ventilation

91. In order to determine whether it is in Pippa's best interests to embark on a trial of portable ventilation with a view to transition to long term ventilation at home, I shall consider the end goal, the means by which that goal might be achieved, and the chances of those means succeeding. However, if the end goal would itself be contrary to Pippa's best interests, then even if there were certainty that it could be achieved, and with minimum of disruption to her care, it could not be considered to be in her best interests to embark on the process leading to it.

92. The starting point is my assessment that it is not in Pippa's best interests to continue with long term ventilation on the PICU. What then would be the differences between prolonging life on the PICU and prolonging life at home? Ms Parfitt submits, through Counsel, that long term ventilation at home would be in Pippa's best interests because it would place her in her home environment, surrounded by her loving family. Reliance is placed on the views of Dr Playfor and Dr Wallis:

> "In common with Dr Playfor, Dr Wallis felt there were benefits to leaving PICU, and that Pippa being cared for in a more suitable domestic setting surrounded by her family, her toys, and her personal objects, was a benefit. He said '*she is capable of receiving love and care, and she gives love and joy to her family. That is her worth'*. Later, he said it was unrealistic to separate mother and child when considering best interests – '*as so often is the case with severe disability and no ability to have a balance sheet, we end up looking at the unit. The mother and child are so enmeshed and tightly bound together that the interests of one affect the other.'*
>
> His view was that the question of where a child should die was '*very much parent-led. It is their right to determine the three most important things: when, how and where does death occur. If you can get those right, you have done well.'*"

93. I fully accept that for a clinician treating a child with severe impairments, it is vitally important to consider the family's wishes and to work, where at all possible, consensually with the family. However, this exceptional case comes to court precisely because that usual approach has broken down. The law is clear: in these cases it is not a parent's right to determine when, how and where death occurs, or whether life sustaining treatment should be prolonged. Nor do I accept that the court should consider Pippa's interests through the prism of her mother's interests: the court is concerned with Pippa's best interests which must be assessed from her perspective, not from anyone else's viewpoint. I referred earlier to Dr Wallis' statement that one of his own patients

was transferred home for palliative care because it was in the "family's best interests." For the court, the focus is entirely on the child's best interests.

94. I have considered very carefully whether, when assessing the best interests of a child with no conscious awareness, I should take any account of the parental view that home is where their child should be cared for, and the parental wish to bring their child home. Mr Sachdeva QC and Ms Butler-Cole QC direct my attention to three authorities: *Re G* [2012] EWCA Civ 1233, *Yates v Great Ormond Street Hospital For Children NHS Foundation Trust* [2017] EWCA Civ 410, and *Re T (Wardship: Medical Treatment)* 1997 1FLR 502.

95. In *Re G,* Munby LJ said:

> "30…The well-being of a child cannot be assessed in isolation. Human beings live within a network of relationships. Men and women are sociable beings. As John Donne famously remarked, "No man is an Island …" Blackstone observed that "Man was formed for society". And long ago Aristotle said that "He who is unable to live in society, or who has no need because he is sufficient for himself, must be either a beast or a god". As Herring and Foster comment, relationships are central to our sense and understanding of ourselves. Our characters and understandings of ourselves from the earliest days are charted by reference to our relationships with others. It is only by considering the child's network of relationships that their well-being can be properly considered. So a child's relationships, both within and without the family, are always relevant to the child's interests; often they will be determinative."

96. In *Yates v Great Ormond Street Hospital,* the Court of Appeal cited with approval the following passage from *Re Z (Identification: Restrictions of publication)* [1997] Fam 1, at page 32:

> "I understood the mother's counsel to advance two reasons why discretion could only be properly exercised to the effect contended for. The first was that the court should never override the decision of a devoted and reasonable parent, such as this mother was found to be. I would from my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment. If that judgment is in accord with that of the devoted and responsible parent, well and good. If it is not, then it is the duty of the court, after giving due weight to the view of the devoted and responsible parent, to give effect to its own judgment. That is what it is there for. Its judgment may of course be wrong. So may that of the parent. But once the jurisdiction of the court is

> invoked its clear duty is to reach and express the best judgment it can."

97. The third authority is that of *Re T*, in which Waite LJ held,

> "All these cases depend on their own facts and render generalisations - tempting though they may be to the legal or social analyst - wholly out of place. It can only be said safely that there is a scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare widely accepted by the generality of mankind; and that at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases at the latter end of the scale, there must be a likelihood (though never of course a certainty) that the greater the scope for genuine debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that 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."

98. I accept that the views of a parent on what is in the best interests of their child should be given due respect and taken into account, but that does not mean that those views should avoid proper scrutiny, let alone that they should be determinative. It is clear to me that the court should also take into account evidence about the family unit and its ability to support a child when assessing best interests, because those matters may directly affect the child’s welfare. Moreover, the court should have regard to a parent’s evidence about the character, values and wishes of their child. However, I do not discern any support in these three authorities for the submission that the wishes of a parent, or any other person, are material to the determination of a child’s best interests in a case of this kind. There is a distinction between the views of a parent as to their child’s best interests or their child’s own wishes, and the independent wishes of the parent. Counsel for Ms Parfitt submit that Holman J’s “sweeping statement” in *An NHS Trust v MB* [see para. 22 above] that parental wishes are “wholly irrelevant” to the objective assessment of a child’s best interests was “simply wrong”. I am unaware of any authority in the fourteen years since his judgment that has expressly cast doubt on Holman J’s view of the law, but I do take into account the judgment of the ECtHR in *Gard and others v UK* (above) to the effect that compliance with Art 2 of the European Convention on Human Rights does require the decision-maker to take into account the wishes of those close to the child when determining the child’s best interests, perhaps all the more so in the case of a young child whose own wishes cannot be ascertained. I also bear in mind that Ms Parfitt has an Article 8 right to family life which ought to be considered. If so, parental wishes are not “wholly irrelevant”. Nevertheless, an objective assessment of a child’s best interests should not be confused with the satisfaction of a parent’s wishes,

even if the wish to care for a child at home is wholly understandable. The child's best interests and parental wishes may coincide, but they may not. In *Re T*, Waite LJ said at page 254

> "when it comes to an assessment of the demands of the child patient's welfare, the starting point - and the finishing point too - must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration. In striking that balance, the judge will of course take into account as a relevant, often highly-relevant factor, the attitude taken by a natural parent, and that may require examination of his or her motives. But the results of such an inquiry, must never be allowed to prove determinative. It is a mistake to view the issue as one in which the clinical advice of doctors is placed in one scale and the reasonableness of the parent in the other."

This approach applies, in my judgement, to all aspects of medical care, including where it should be given.

99. In *Yates v Great Ormond Street Hospital* [2017] EWCA Civ 410, [2018] 1 All ER 569, at [95] McFarlane LJ summarised the proper judicial approach,

> "When thoughtful, caring, and responsible parents are putting forward a viable option for the care of their child, the court will look keenly at that option, in the same way that a court in family proceedings, when it gets to the welfare stage of any case, looks at the realistic options that are before it. The court evaluates the nitty-gritty detail of each option from the child's perspective. It does not prefer any particular option simply because it is put forward by a parent or by a local authority. The judge decides what is in the best interests of the child by looking at the case entirely through eyes focused on the child's welfare and focused upon the merits and drawbacks of the particular options that are being presented to the court."

100. Accordingly, the court should take into account the wishes of those close to Pippa to care for her at home but only as part of the broad assessment of Pippa's best interests, and without detracting from the fundamental principles that Pippa's welfare is my paramount consideration and that the assessment of best interests is made from her perspective. If it would be contrary to Pippa's best interests to be cared for on long term ventilation at home, then it would be lawful not to accede to her family's wishes in that regard, and unlawful to do so. Their Article 8 rights would not be contravened. Dr Playfor, Dr Wallis, and many other people might think that when a child can feel no pain, the courts should seek a solution that gives the most comfort to the child's family, and that there is a cruelty in depriving them of that comfort and curtailing the life of the child they cherish. But the law seems to me to be clear that the benefits that Pippa has brought, and may continue to bring, to others, and the satisfaction of the wishes of a child's family, are not the focus of the court's attention. It is her welfare that is

paramount, not the welfare of others, and her best interests that are the court's concern. Commenting on the judgment in *Raqeeb*, Hayden J said in *Birmingham Women's and Children's NHS Foundation Trust v JB and KAB*, [2020] EWHC 2595 (Fam),

> "I am confident that Macdonald J, in *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530 (Fam) did not for a moment intend that a Trust should ever approach an evaluation of a child's best interests, in the context of medical treatment, as secondary to the wishes or religious beliefs of the parents. That would subvert the framework of the established law which preserves the interests of the child as paramount. Nor do I believe Macdonald J intended to sever medical 'best interests' from an overall evaluation of the child's interests. Such an approach would be artificial. A true and meaningful assessment of a child's best interests requires a conscientious survey of the wide canvas of his life, in which process the views of his parents concerning matters of faith, culture and more widely will be important but never a determinative factor."

101. Transfer to home care would not benefit Pippa's medical condition. Ms Parfitt's belief is that Pippa's condition will improve with home care, but I cannot accept that belief as a reasonable foundation for the proposition that it is in Pippa's best interests to receive long term ventilation at home. Extensive medical evidence has been adduced, and there is none which shows that changing Pippa's environment from hospital to home will lead to any improvement in her condition. She will remain unaware of her environment or of interactions with others. She would not be aware, therefore, of any change in her environment from the PICU to home and she would receive no benefit from such a change.

102. There would be some differences between the healthcare given in the PICU and any ongoing healthcare at home. The medical, nursing and physiotherapy care at home could not be of the exceptional standard it is in the PICU. Even if it is assumed that the very best care package could be funded and provided in Pippa's family home, a home ventilator cannot provide the same sophisticated level of finessed support as a PICU ventilator, there could be no use of anaesthetic bagging and more advanced respiratory physiotherapy techniques, and the immediate availability of a respiratory physiotherapist would not be guaranteed. Even assuming that a tracheostomy and transfer to home ventilation somehow improved Pippa's stability, there would be significant risk of a fatal complication occurring at home within weeks of transfer there, and without the immediate availability of the requisite equipment and skilled personnel effectively to help her. Pippa's home care could never replicate the exceptional standards of PICU care and in that sense transfer home would, if anything, be a detriment to her. However, if it is assumed that long term ventilation at home could safely be given without the need for anaesthetic (pressurised) bagging and saline lavage, Pippa would be at least spared those particular interventions which, I have found, are amongst the invasions of her bodily integrity that do constitute a detriment to her.

103. I cannot discern any non-medical benefit to Pippa's welfare from her care being at home rather than in a hospital. In his first report, Dr Wallis wrote,

> "If the clinical trial and move to a step-down unit was successful, I consider it would be in the child's best interests to then move home with a long term ventilation package of care, as this would give her a more appropriate environment in which to live and receive such life sustaining support and enjoy the daily benefits of close family life."

Dr Wallis and Dr Playfor each told me that they do not think it in Pippa's best interests to continue life sustaining treatment within a PICU. For both of them, the benefits of family life at home are what change the balance of best interests from withdrawing to continuing life sustaining treatment. Acknowledging their considerable experience in dealing with gravely ill children, I cannot agree with them.

a. I accept that there would be differences in the environment in which care were delivered to Pippa if she were transferred home. Attempts are made to personalise Pippa's environment on the PICU. As I saw on visiting her, she has her own clothes, and duvet. She is surrounded by her own toys, and coloured lights. She has music or videos played to her. Her mother is by the bedside sixteen hours a day and contributes very effectively to her nursing care. Nevertheless, inevitably there is a clinical sterility in the PICU. It is spacious but there are other children and parents in the vicinity. The PICU is a busy place with healthcare professionals constantly coming and going. At home the environment would be more personal, perhaps more peaceful.

b. It would be wrong, however, to imagine that Pippa's home would be anything like a normal home if she were returned there on long term ventilation. Much of her home would in effect become a mini-hospital with a large team of specialist nurses working shifts, and therapists visiting on a regular basis. Specialist equipment such as a hoist, tilting table, specialist chair, cough assist machine, ventilator, monitors and a hospital bed would be installed, and all manner of sterilised pieces of clinical paraphernalia stored. Two nurses would be on duty at all times. She would be attached to a ventilator and monitored using electronic equipment and she would continue to require suctioning, proning and other interventions, day and night. She would be fed through a gastrostomy. She would need hygiene care as now. Pippa's immediate environment would in many ways be similar to that at the PICU and, for her, home life would have many of the same features as life in the PICU.

c. It is agreed by all the medical witnesses that Pippa has no conscious awareness of her environment or interactions with others. Therefore, there would be no benefit to her from being in a home bedroom as opposed to a hospital unit. Family members may be able to spend more time with her at home in a more peaceful and welcoming environment, but she would not be aware of their visits or of the benefit to others. She would not be aware of any of the changes in her environment or in her care regime.

104. Pippa would continue to bear nearly all of the burdens of her condition and treatment that she has on the PICU were she to receive long term ventilation at home. Having regard to all the evidence, including the views of Ms Parfitt, I am not satisfied that home care would confer any benefits to Pippa's welfare. Any benefits of home care that do exist would fall to her family, rather than to Pippa because she has no conscious awareness and derives no benefit from interactions with others, including family members. That is not to say that Ms Parfitt's advocacy of home care is motivated by her own needs – no-one could have been more selfless in her devotion to her daughter. But I have to focus on Pippa's welfare and so it is necessary to be clear as to the benefits and burdens to her of home care, as opposed to PICU care. As to the benefits to the family, I proceed on the basis that Ms Parfitt speaks for the whole family, but I am not in a position, nor would it be appropriate, to take a view as to the other child involved in the decisions before the court, namely Pippa's seven year old brother.

105. Looking at the wider question of whether home care, as opposed to PICU care, would serve Pippa's best interests, I accept that I should take into account the wishes of Pippa's family to care for her at home, and that home care is a goal that, as a much loved five year old girl, Pippa would be likely to share. As a generality it is in a young child's interests to be cared for by a loving family, living with them at home, rather than away from home.

106. Standing back to consider and balance all welfare considerations and factors affecting best interests, I am sure that it would be detrimental to Pippa's welfare and contrary to her best interests to receive long term ventilation at home, assuming that home care is a feasible option.

a. The first matter I take into account is the preservation of Pippa's life. In fact, home care would be a less effective means of prolonging life than care in the PICU because the standard of care on the PICU could not be matched. However, that is an artificial comparison if the alternative to attempting a transfer to home care is to withdraw ventilation. Long term ventilation at home, if achievable, would at least serve to prolong Pippa's life, albeit only for "some months".

b. Weighed against the prolongation of life is the fact that long term ventilation at home would not improve Pippa's underlying neurological condition. She would remain unaware of her environment and interactions with others and remain unable to derive any pleasure from life. Prolonging her life at home would be no more beneficial to Pippa's welfare than prolonging her life in the PICU.

c. Pippa would continue to suffer the burdens of her condition and the treatment it requires. She might be spared some of the interventions currently performed on her in the PICU such as saline lavage, but she would need a tracheostomy and gastrostomy which she does not currently have. At home she would continue to receive artificial nutrition and hydration, therapies to protect her bones and muscles, 24 hour nursing care, ventilation, suction, cough assist, turning, proning, and bagging. Prolonging her life by long term ventilation at home would prolong those burdens.

d. I take into account the wishes of Pippa's mother to care for her at home, that Pippa would have been likely to have wanted to be at home rather than in hospital, and that there might be some benefits to Pippa's family from home care as opposed to hospital care, but Pippa would not be aware that her family were benefiting, their welfare is not the focus of the court's consideration, and although Pippa may well have wanted to be cared for at home, she would not be aware that she was at home.

e. I cannot give weight to Ms Parfitt's view that home care would improve Pippa's condition, because it is at odds with the unanimous view of the clinicians and medical experts.

Dr Wallis asks what is there to lose by trying to transfer Pippa to home ventilation if the alternative is withdrawal of life sustaining treatment? The answer is that the loss would be the continuing burdens to Pippa caused by maintaining a regime of ventilatory support and other life sustaining treatment to prolong her life, when to do so would bring her no benefit. Pippa's welfare is my paramount consideration and continued ventilation, whether in the PICU, a transition unit, or at home, is detrimental to her welfare. Even allowing for a very broad assessment of Pippa's medical and non-medical interests, the presumption that life should be preserved is rebutted in this case.

107. In my judgment, therefore, long term ventilation at home would be contrary to Pippa's best interests. In any event, I have already found that the chances of success of both a trial of portable ventilation, and then a transition process, are remote. Furthermore, the transition process is prolonged – it would take at least six months. During that time Pippa would continue to be ventilated and treated in a hospital setting. She would not therefore have any of the supposed benefits of home care during that process. Her life expectancy on long term ventilation once at home would be uncertain but the best evidence is that it would be for some months only. It might be as short as a matter of weeks. At any time she could suffer a complication from which she could not recover, and the means available to achieve her recovery in the community would be less effective than those available in the PICU. In my judgement, balancing all the relevant factors including the views and wishes set out above, the presumption that life should be preserved, the benefits and burdens to Pippa of long term ventilation at home, the fact that she would remain without conscious awareness and would have no hope of improvement, the remote chance of the goal of home care being achieved, her limited life expectancy on home ventilation, and the long process involving continued ventilation in a hospital setting that would be required before home care could begin, I have reached the firm conclusion that it is not in her best interests to embark on a trial of portable ventilation and the transition process towards home care.

108. I referred earlier to two strands of thought regarding the best interests assessment of a patient in a permanent or persistent vegetative state. In accordance with the submissions of all the parties in this case I have endeavoured to consider benefits and burdens to Pippa that go beyond those of which she is conscious, and to consider her interests in the broadest possible sense. The other view is that there is no balancing exercise of burdens and benefits because the individual has no conscious awareness. Had I taken that approach I would have reached the same conclusion that long term ventilation is not in Pippa's best interests, wherever she was cared for, and that it is not in her interests to embark on a trial of portable ventilation with a view to transferring her to long term ventilation at home.

Declarations

109. For the reasons given I am satisfied that it is in Pippa's best interests to withdraw mechanical ventilation, it being contrary to her best interests for it to be continued. On extubating Pippa it is likely that she will survive a very short time only. On withdrawal of ventilation there should be defined limits on the treatment provided to Pippa to allow her to die – those limits will be set out in the Court's Order following this judgment. If ventilation is to be withdrawn then it may be that Ms Parfitt will wish that to be done at home. The Trust has told me through Dr C that extubation can be arranged to take place at home with support from trained and experienced hospital personnel to transfer her home and then to undertake the extubation process and to provide such palliative care as may be necessary in the very short time that Pippa will remain alive. As I understand it the portable ventilation necessary for transporting her home would be expected to be used only for a matter of hours. I do not know if Ms Parfitt would want to bring Pippa home for that purpose but I very much hope that with the support of the Guardian and others she can work with the Trust to agree on the circumstances of withdrawal of ventilation.

110. I am satisfied that it is not in Pippa's best interests to undergo a tracheostomy. It would serve no useful purpose, provide no benefit to her, and it would be an unnecessary intervention. By the conclusion of the evidence it was accepted by Dr Wallis that the two week trial of portable ventilation could be done without performing a tracheostomy. Thus, the prospect is put before the court of a supposedly "harmless" two week trial of portable ventilation which would be likely to fail but which it is claimed would at least give Ms Parfitt the peace of mind that everything had been tried that could be tried. The Second Respondent proposes that the court makes a declaration that it is lawful and in Pippa's best interests to undergo a trial of portable ventilation at the Evelina in a two-stage process, "starting with a trial without a tracheostomy".

111. Having given the matter careful consideration, I am not prepared to adjust the declarations I make to accommodate that suggestion. Most importantly, I have already concluded that continuing ventilation is contrary to Pippa's best interests. A trial of portable ventilation might not involve a tracheostomy but it would involve continuing ventilation on the PICU albeit for a short period. The trial would confer no benefit on Pippa. Furthermore, I am concerned that such an attempt to give Ms Parfitt some comfort would be ill-judged. Firstly, there are ongoing disagreements about how the trial should be conducted and failure of the trial could well lead to further disagreements about the merits of a re-trial with further adjustments. Secondly, Ms Parfitt does not agree that Pippa has made no progress to date and may well take a different view from the clinicians about whether Pippa had responded to the trial and whether everything had been done that could have been done. Thirdly, for the reasons I have set out in detail in this judgment, it would remain in Pippa's best interests to withdraw ventilation even after a successful trial of portable ventilation. Withdrawal after a successful trial might, if anything, aggravate the distress to Pippa's family.

112. Ms Parfitt has fought as hard for Pippa as any parent could. Responsibility for the decisions in this case lies with the court not with her. My conclusion is that continued

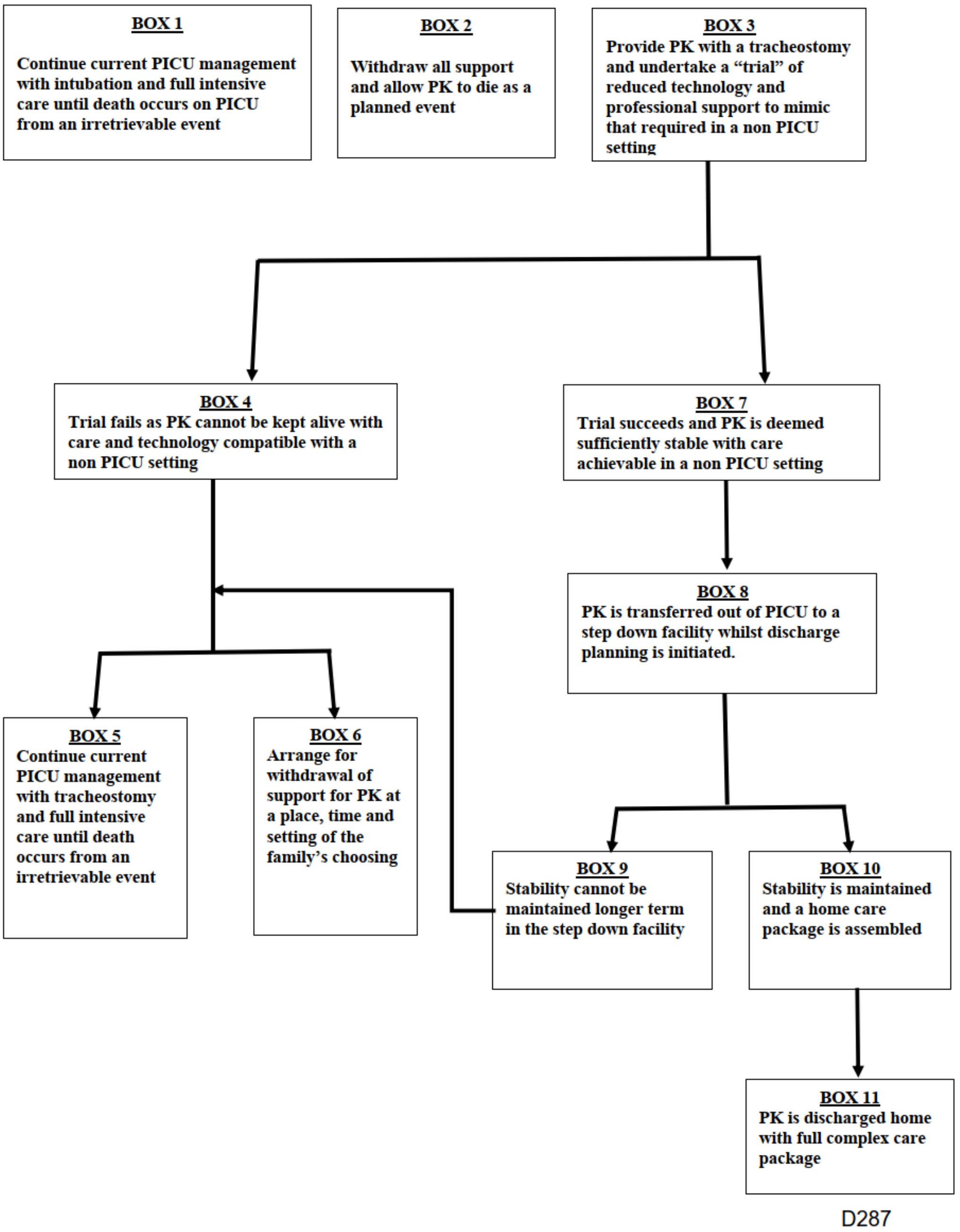
mechanical ventilation is contrary to Pippa’s best interests. The declarations sought, and which I shall make, are not in contravention of Pippa’s Art 2 right to life and constitute necessary and lawful interference with her and her mother’s Art 8 rights to family life. The declarations include a declaration that it would be lawful and in Pippa’s best interests for mechanical ventilation to be withdrawn. The precise circumstances in which mechanical ventilation is withdrawn are a matter now for agreement but it would not be contrary to Pippa’s best interests to transfer her to her family home for the purpose of withdrawal of ventilation.

113. The declarations I make are that it is lawful and in Pippa’s best interests that:

(a) She should not be provided with a tracheostomy.
(b) Mechanical ventilation should be withdrawn.
(c) There be clearly defined limits on the treatment provided to Pippa after that withdrawal of ventilation, with the effect that she would be allowed to die.

Appendix 1

Possible options and outcomes for PK:



BOX 1
Continue current PICU management with intubation and full intensive care until death occurs on PICU from an irretrievable event

BOX 2
Withdraw all support and allow PK to die as a planned event

BOX 3
Provide PK with a tracheostomy and undertake a "trial" of reduced technology and professional support to mimic that required in a non PICU setting

BOX 4
Trial fails as PK cannot be kept alive with care and technology compatible with a non PICU setting

BOX 7
Trial succeeds and PK is deemed sufficiently stable with care achievable in a non PICU setting

BOX 8
PK is transferred out of PICU to a step down facility whilst discharge planning is initiated.

BOX 5
Continue current PICU management with tracheostomy and full intensive care until death occurs from an irretrievable event

BOX 6
Arrange for withdrawal of support for PK at a place, time and setting of the family's choosing

BOX 9
Stability cannot be maintained longer term in the step down facility

BOX 10
Stability is maintained and a home care package is assembled

BOX 11
PK is discharged home with full complex care package

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