Neutral Citation Number: [2021] EWCA Civ 362

Case No: B4/2021/0124

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE HIGH COURT OF JUSTICE
FAMILY DIVISION
The Honourable Mr Justice Poole
FD20P00135

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 19 March 2021

Before :

LADY JUSTICE KING
LORD JUSTICE BAKER
and
LADY JUSTICE ELISABETH LAING

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IN THE MATTER OF THE SENIOR COURTS ACT 1981
AND IN THE MATTER OF PIPPA KNIGHT (A CHILD)

Between :

PAULA PARFITT	**Appellant**
- and -	
(1) GUY'S AND ST THOMAS' CHILDREN'S NHS FOUNDATION TRUST **(2) PIPPA KNIGHT (by her children's guardian)**	**Respondents**

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Vikram Sachdeva QC, Victoria Butler-Cole QC and Catherine Dobson (instructed by **Sinclairslaw**) for the **Appellant**
Michael Mylonas QC (instructed by **Hill Dickinson LLP**) for the **First Respondent**
Neil Davy (instructed by **Cafcass Legal**) for the **Second Respondent**
Hearing date : 9 February 2021

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Approved Judgment

Covid-19 Protocol: This judgment was handed down remotely by circulation to the parties' representatives by email, release to BAILII and publication on the Courts and Tribunals Judiciary website. The date and time for hand down is deemed to be 10.30am on Friday 19 March 2021.

LORD JUSTICE BAKER:

Introduction and summary

1. This is a profoundly sad and moving case about the life of a small child.

2. Pippa was born in April 2015 into a loving family. She has a brother who is two years older than she. When she was 20 months old, she was diagnosed with a rare and usually terminal condition known as acute necrotising encephalopathy ("ANE"), probably caused by a viral infection, from which she suffered very severe brain damage. Over the next few months, her health deteriorated rapidly. She is now totally dependent on mechanical ventilation and has respiratory instability with frequent desaturations requiring specialist nursing and physiotherapy interventions. She is doubly incontinent and has cortical blindness.

3. Shortly after Pippa's second birthday, her father, who had previously lost a child during an earlier relationship, took his own life. Her mother, supported by other family members, has devoted her life to Pippa, looking after her herself for as long as possible. During the last two years when Pippa has been continuously in hospital, her mother has lived in hospital accommodation and spent up to 16 hours a day by her bedside. Pippa's brother is living with his grandmother and is having video calls with his sister, but because of restrictions imposed under the Covid-19 regime has not visited the hospital since February 2020.

4. Through the dedication and skill of doctors, nurses, therapists and other hospital staff, Pippa has received medical and nursing care of the highest quality but, despite their efforts, she has slipped into a persistent vegetative state ("PVS"). The medical evidence indicates that almost certainly she neither feels pain nor is able to experience pleasure and that there is no prospect of any improvement in her condition. Her mother disagrees, believing that there are signs of improvement and that Pippa shows an awareness of her family and circumstances from which she is capable of deriving pleasure.

5. When a disagreement about a child's medical treatment arises between doctors and the family, an application may be made to the court to resolve the dispute. When considering such an application, the judge must exercise his own independent and objective judgment about what is in the child's best interests. In this case, on 9 March 2020, the NHS Trust ("the Trust") responsible for the hospital where she is being treated, the Evelina London Children's Hospital, applied to the court for declarations and orders that would permit the withdrawal of life-sustaining treatment. Her mother opposed the application and instead proposed that Pippa should return home. It was common ground that in order to have any chance of being managed in a home environment, Pippa would require a tracheostomy to deliver ventilation safely and that she would need to be transferred to a portable ventilator which could be used in a step-down unit and subsequently at home. The mother sought the court's approval for a trial of portable ventilation to establish whether Pippa was sufficiently stable to return home.

6. The application came before Poole J shortly before Christmas 2020. Before the judge and before this Court, the parties have been represented by lawyers who are very experienced in cases involving decisions about serious medical treatment. The judge had the benefit of evidence from a number of highly respected specialist doctors. This

is not a case where any of the parties has relied on evidence from outside the mainstream of orthodox medical opinion. The treating clinicians who gave evidence included 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 Paediatric Intensive Care Unit ("PICU"), Dr B, the lead consultant paediatric neurologist, Dr C, a respiratory consultant, who has led Pippa's respiratory care, and Ms F, a clinical specialist paediatric respiratory physiotherapist. The hospital clinicians were unanimously of the view that the mother's proposal was contrary to Pippa's best interests. But some of the independent specialists instructed with the court's leave took a different view. These included Dr Colin Wallis, a consultant respiratory paediatrician at Great Ormond Street Hospital for Children, Dr Stephen Playfor, a consultant paediatric intensivist at the Royal Manchester Children's Hospital, and Dr Michelle Chatwin, a consultant paediatric respiratory physiotherapist at the Royal Brompton Hospital. It was Dr Wallis who first suggested that it might be possible to transfer Pippa home on long-term ventilation, a proposal supported by Dr Playfor and Dr Chatwin.

7. At the conclusion of the hearing, the judge reserved judgment which he considered and drafted over Christmas and delivered on 8 January 2021. After a comprehensive analysis which was characterised by great insight and humanity, he concluded that the Trust's application should be granted and made declarations that it was lawful and in Pippa's best interests that (a) she should not be provided with a tracheostomy, (b) mechanical ventilation should be withdrawn, and (c) there be clearly defined limits on the treatment provided to her after the withdrawal of ventilation, with the effect that she would be allowed to die.

8. The mother filed a notice of appeal citing four grounds of appeal and on 25 January 2021 my Lady, King LJ, listed the application for permission to appeal for hearing with appeal to follow if permission were granted. Proceedings before the Court of Appeal involve a review of the judge's decision, not a full rehearing of the case. The law provides that this Court can only allow an appeal where it concludes that the judge's decision was wrong or that there had been a serious procedural or other irregularity. No one has suggested that there was any irregularity in this case. In simple terms, the question for us is whether the judge's decision was wrong.

9. The judge's decision was rightly based on his assessment of Pippa's best interests because her welfare in the widest sense is the paramount consideration. He looked at all the evidence, including importantly the views of her family, in particular her mother who has dedicated her life to Pippa and fought so hard to find a way of keeping her alive. Having considered all the evidence, the judge concluded that it was not in Pippa's best interests to continue to receive life-sustaining treatment nor to embark on a trial of portable ventilation which if successful could lead a transition process, carried out over a number of months, towards home care.

10. In my view, the judge's decision was not wrong. Having considered all the evidence drawn to our attention and the submissions made to us, I am satisfied that he was right. For the reasons set out in detail below, I would refuse permission to appeal on three of the four grounds. On the fourth ground, I would grant permission to appeal but dismiss the appeal.

The law

11. Cases in this jurisdiction involving applications to withdraw life-sustaining treatment for patients, in particular children, have attracted national and sometimes international attention, most notably the proceedings involving Charlie Gard, which included the hearing before this Court in May 2017 leading to the judgment reported as *Yates v Great Ormond Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, [2018] 4 WLR 5 ("*Yates*"). The media and the wider general public are understandably and properly interested not only in the human stories lying at the heart of every case but also about the process by which these difficult decisions are made. Each case requires care and attention of the utmost sensitivity.

12. The legal principles, however, are clear and well established. As my Lady pointed out in *Re A (A Child)* [2016] EWCA Civ 759, a case involving the withdrawal of treatment from a child, the principles were succinctly summarised by Baroness Hale of Richmond in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591, a case concerning an adult patient receiving clinically-assisted nutrition and hydration. At paragraph 22 she said:

> "…the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."

At paragraph 39, Baroness Hale continued:

> "The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

Further on, at paragraph 42, Baroness Hale summarised the role of the appellate court in such cases:

> "if the judge has correctly directed himself as to the law, as in my view this judge did, an appellate court can only interfere with his decision if satisfied that it was wrong: *Re B (A Child) (Care*

> Proceedings: Appeal) [2013] UKSC 33. In a case as sensitive and difficult as this, whichever way the judge's decision goes, an appellate court should be very slow to conclude that he was wrong."

13. The approach to be adopted by a court conducting the necessary balancing exercise was summarised by Holman J in *An NHS Trust v MB* [2006] EWHC 507, [2006] 2 FLR 319, in a passage (at paragraph 16 of the judgment) that has been cited in many later cases, including by Poole J in the present case:

> "i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.
>
> ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.
>
> iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.
>
> iv) The matter must be decided by the application of an objective approach or test.
>
> v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.
>
> vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.
>
> vii) Considerable weight (Lord Donaldson of Lymington MR referred to "a very strong presumption") must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.
>
> viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of

> Lymington in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:
>
> > '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. We all believe in and assert the sanctity of human life …. Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.'
>
> ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.
>
> x) The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

14. The approach was succinctly summarised by this Court in *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 where the judges, having considered various earlier authorities including *Re J (A Minor) (Wardship: Medical Treatment*, [1991] Fam 33, and *Re A (Male Sterilisation)* [2000] 1 FLR 549, summarised the legal principles in these terms (at paragraph 87):

> "the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (*Re J*). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (*Re J*). The term 'best interests' encompasses medical, emotional, and all

> other welfare issues (*Re A*). The court must conduct a balancing exercise in which all the relevant factors are weighed (*Re J*) ….”

15. A number of further reported cases were cited to us, some of which are considered below when dealing with the grounds of appeal. The only other authority to which I should refer at this stage is *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2530 (Fam), [2020] 3 All ER 663, (“*Raqeeb*”), which was cited at a number of points in the appellant’s submissions. It concerned a five-year-old girl, Tafida, who was being kept alive by artificial ventilation in a Trust hospital after sustaining irreversible brain damage. The medical evidence demonstrated that she was unlikely to experience pain and was, at best, only minimally aware. Although she was unlikely to recover, it was anticipated that, if kept on mechanical ventilation, she would live for a further ten to twenty years. The Trust’s clinicians concluded that it was not in her best interests to continue the life-sustaining treatment. The parents, however, disagreed, in part because the withdrawal of treatment went against their religious beliefs. They contacted doctors at an Italian hospital who, whilst not believing that the child could be “cured”, offered to carry out a course of treatment including a tracheostomy which would allow Tafida to be cared for at home on a ventilator. The child, through a litigation friend, sought judicial review of the Trust’s refusal to agree to her being transferred to the Italian hospital.

16. MacDonald J refused the Trust’s application for a declaration and granted the child’s application for judicial review, although for reasons which are irrelevant to the present appeal, he declined to grant any relief on the child’s application. His judgment traversed a number of legal issues but the passages cited to this Court relate only to his approach to the determination of best interests, and in particular the analysis of the benefits and burdens of the treatment programme. With regard to benefits, he said:

> “171. …. I accept that there is some force in the Trust’s submission as to the minimal or absent medical benefit in continuing to maintain Tafida with life sustaining treatment. Within this context, a further important factor supportive of the Trust’s application is the fact that the care proposed by the Gaslini Hospital in Italy is substantially the same as that currently being given to Tafida by the Trust and will not result in any substantial improvement in her condition ….
>
> 172. Against this, 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.
>
> 173. Within this context, and again having regard to the medical consensus of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction, the benefits for Tafida of continued life sustaining treatment include being at home, being in the care of her loving and dedicated family, and, insofar as she is minimally aware, gaining from such awareness as she has of those matters. Further, I accept the submission that within the religious and cultural tradition in which Tafida was being raised, and whilst not by itself sufficient to justify the continuation of life sustaining treatment on the basis of Art 9 or otherwise, a further benefit of continued life sustaining treatment is that it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised and for which she had begun to demonstrate a basic affinity."

17. As for the burdens, MacDonald J made these observations:

> "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] EWCOP 76, 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. Within this context, the question of whether continued treatment would burden Tafida 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."

18. At paragraph 182 of his judgment in ***Raqeeb***, MacDonald J concluded:

> "… in circumstances where Tafida is not in pain, where the burden of the treatment is low, where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to her being cared for at home on ventilation by her family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction, where there is a funded care plan to this end, where Tafida can be safely transported to Italy, where the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised and having regard to the sanctity of Tafida's life, this case does in my judgment lie towards the end of the scale where the court should give weight to the reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of the child's life will be taken for the child by a parent in the exercise of their parental responsibility. Further, whilst I did not hear detailed submissions on the import of Art 8 of the ECHR in the context of this case, and whilst the Art 8 rights of the parents are subordinate to the best interests of the child where the two conflict, in the circumstances I have just summarised there is in my judgment a cogent argument that the making of orders the effect of which would be to override the choice made by the parents in the exercise of their parental responsibility would not constitute a necessary and proportionate justification for the interference in their Art 8 rights that would thereby occur."

The proposal of a trial of portable ventilation

19. Both the treating clinicians and the experts instructed independently for the hearing are in agreement that the continuation of life-sustaining mechanical ventilatory support and treatment within the PICU setting is not in Pippa's best interests and they would therefore each support the withdrawal of treatment.

20. The central issue in the present case is whether the court should authorise a trial of portable ventilation with a view to Pippa returning home notwithstanding the

challenges such a course would present. This would be with a view to her remaining on a ventilator at home for what would be likely to be a relatively short period of time given that it is inevitable that the medical care that Pippa would receive at home, whilst dedicated and loving, cannot hope to match that available in the PICU where Pippa has been cared for the last two years.

21. It should be made clear that this proposal is different from any arrangement for Pippa to be transferred home in the immediate future with a view to ventilation being removed shortly afterwards in order to allow her to die at home with her family around her. That is an arrangement that the hospital are both able and willing to facilitate.

22. The proposal for long-term ventilation at home was first put forward by Dr Wallis in his initial report in April 2020. Although Pippa has respiratory instability with frequent desaturations which require specialist nursing and physiotherapy interventions, Dr Wallis expressed the opinion in his report that Pippa could be safely managed outside a critical care unit:

> "[Pippa] requires a high level of nursing, physiotherapy and technological support. Although management outside of a critical care unit can never be as safe as the 1-1 multiprofessional support that she receives within an intensive care [environment], if certain parameters were in place and conditions were met, it could be possible to manage [Pippa] in a non-intensive care environment."

He advised that a number of steps would have to be taken to be managed in a home environment or step-down unit. First, she would need a tracheostomy to safely deliver ventilation. Secondly, she would need to be transferred to a portable ventilator for use at home or in a step-down unit and it would need to be demonstrated that this ventilator could maintain her respiration and gas exchange. Thirdly, Dr Wallis thought Pippa would benefit from a gastrostomy in preference to her current nasogastric tube feeding. Fourthly, she would need a team of carers and relatives present 24 hours a day including a nurse or similarly-trained carer at all times with probably one other additional trained person present. This high level of care package was required because of her episodic desaturations. Carers and nurses would need to be trained and competent in all aspects of her care, including chest physiotherapy which is not regularly available in a community setting. A period of observation would be required to ensure that carers were able to provide effective intervention in the home setting.

23. In his report, Dr Wallis concluded:

> "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 …. Although she is at the outer limits of possibility, living at home might be possible …. 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 and receive such life-sustaining support and enjoy the daily benefits of close family life."

Dr Wallis illustrated his proposals of the steps to be taken towards home care in a flowchart which the judge attached to his judgment as Appendix 1. In the notes to the flowchart, he acknowledged that the process of assembling a complex care package for Pippa would take "many months" because of her high needs.

24. In oral evidence, Dr Wallis suggested for the first time a number of additional measures which could be taken to address Pippa's episodes of substantial desaturation – increasing the ventilation, raising the level of oxygen administered, increasing suctioning, entraining oxygen into a bag from a concentrator, and moving onto a so-called AMBU bag commonly used in the community. These late additions to Dr Wallis's evidence gave rise to difficulties which were considered in the judgment as I shall illustrate below.

25. Following the production of Dr Wallis's report, the Trust's clinicians raised a number of concerns about the proposal. Despite their view that such a course would not be in Pippa's best interests, they produced a draft protocol for implementing the trial. Dr Wallis and Dr Playfor, who supported the proposal, thought the protocol was too limited and designed in a way that was set up to fail. Dr Playfor thought the Trust's suggested plan for supporting Pippa at home was too prescriptive:

> "No child mechanically ventilated in a domestic setting receives care of an equivalent standard to that delivered in a Paediatric Critical Care Unit. For a child in [Pippa]'s position, a genuine trial of the feasibility of portable mechanical ventilation requires a flexible and pragmatic iterative development of an individualised, structured plan for mechanical ventilation and associated interventions."

Dr Chatwin gave some support to the proposal. She agreed with the list of services identified by Dr Wallis as to what would be required if Pippa were to be moved. She concluded in her report:

> "If this management strategy outlined above is deemed in [Pippa]'s best interests and [Pippa] is successfully cared for in a step down unit or high dependency unit, I agree with Dr Wallis that a long term ventilation package of care should be sought. In my opinion being in the home rather than a critical care unit would provide the daily benefits of close family life, which cannot occur in critical care. As previously stated, the family should have a full understanding that the care provided at home is not to the same standard as within the critical care environment. It is possible that this would mean that PK only has a short period of time at home but the benefit for her would be that she is with all her family. Being with her family is something that is also very difficult at the present time due to the Covid-19 situation."

The judgment

26. After summarising the background to the case, the judge identified the issues in these terms:

> "16 In my judgment, 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."

He noted that none of the clinical or expert witnesses had contended that option A would be in Pippa's best interests, but he found it necessary to consider it because her mother said in evidence that she would prefer option A to option C. Thus, were he to determine that option B should be preferred, the trial home might well fail leaving the parties remaining in dispute about whether continued ventilation in the PICU was in Pippa's best interests.

27. He set out his approach to option B at paragraph 17:

> "… 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."

28. The judge then set out the legal principles, citing passages from a number of the reported authorities. He quoted from professional guidance, including the definition of vegetative state and minimally conscious state in the guidelines published by the Royal

College of Physicians "Prolonged disorders of consciousness following sudden onset brain injury" (2020) and advice about the limitation and withdrawal of treatment in guidance approved by the Royal College of Paediatrics and Child Health and published in the form of an article on the Archives of Disease of Childhood, "Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice" (Larcher and others, Arch Dis Child 2015).

29. The judge then set out the evidence about Pippa's condition. He summarised the consensus of the clinicians and expert witnesses as follows (at paragraph 32):

> "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.
>
> d. On the balance of probabilities Pippa cannot derive any pleasure from her environment or interaction with others.
>
> 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."

30. The judge summarised the evidence about various aspects of her condition. With regard to her respiratory condition, he recorded that she was unable to breathe for herself and was dependent on mechanical ventilation. Currently this was being administered via an endotracheal tube ("ETT") rather than a tracheostomy tube. The particular challenges with her respiratory condition were not related to ventilation in itself but rather to her tendency to desaturate – for her oxygen saturation to fall – because she has poor oxygen reserve and a tendency for her lungs to collapse ("atelectasis") and secretions and saliva accumulate in her airway because she cannot swallow or cough and has no gag reflex. To address these problems, she receives regular respiratory physiotherapy, and spends at least two hours a day in a prone position to remove pressure on the back of her lungs

and build up her oxygen reserves. She also receives assistance two or three times a day from a cough-assist machine, administering saline under pressure and then reversing the flow to stimulate a cough, and undergoes a process called saline lavage. Even with these interventions, Pippa experiences desaturations every one to four hours, which are treated in a variety of ways including by deep suctioning, by adjustments to the ventilator pressures, and by the use of anaesthetic bagging which introduces oxygen under pressure. Once a week, she experiences a more serious episode of desaturation when her level of oxygen drops significantly below 80%.

31. At paragraph 42, the judge summarised her prognosis in these terms:

> "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."

32. The judge then considered Dr Wallis's proposal for a trial of portable ventilation with a view to transition to home care. Before considering the substance of this proposal, he expressed some dissatisfaction about the way the proposal had been presented:

> "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."

The judge's decision to refuse to admit Dr Chatwin's fourth report submitted after the hearing is one aspect of the fourth ground of appeal which the appellant seeks to pursue before this Court.

33. At paragraph 45, the judge then summarised Dr Wallis's proposal by reference to his initial report. At paragraph 46 of his judgment, the judge summarised the conflicting opinions of the clinicians and other medical experts and set out what had been 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 .... 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….
>
> (h) When home care has been replicated, and the home care package is assembled, Pippa would be ready to be transferred home ….
>
> (i) … [W]ere 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'."

34. The whole process of trial and transition would take at least six months. It was Dr Wallis's view that overall there was a 1 in 4 chance of Pippa reaching the point of being discharged home, but if the initial trial were successful there would then be a 90% chance that she would progress from the transition unit to home. Once there she would continue to receive ventilation with the intention of keeping her alive as long as possible. All the medical witnesses agreed, however, that Pippa's life expectancy would be shorter if cared for at home than if she remained under her current treatment regime in the PICU, because of the limits of what can be provided in the home setting.

35. The treating clinicians did not agree with Dr Wallis's proposal. It was their combined view that there was no realistic chance that, with less sophisticated equipment and less specialist personnel, she could survive more than a very short time at home. They would not be willing to perform a tracheostomy for the purpose of a trial, believing that the exercise would be futile. It was the Trust's view that Pippa could not be cared for safely outside the PICU. At paragraph 49, the judge summarised the reasons for this view:

> "(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).”

36. As to the latter point, the judge (at paragraph 51(b)) noted that:

> “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.”

37. At paragraph 51(d), the judge considered certain possible adjustments to Pippa's care which Dr Wallis had "politely suggested" in his oral evidence might optimise the chances of a successful trial of portable ventilation and to which some of the Trust witnesses had responded in evidence. The judge summarised the proposed adjustments as

> "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".

He continued (at paragraph 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."

The judge's approach to Dr Wallis's proposals for adjustments to the treatment programme is a further aspect of the fourth ground of appeal which the appellant seeks to pursue before this Court.

38. The judge noted that in his report Dr Wallis had described Pippa's clinical condition as being "at the absolute outer limits of what might be achievable at home." In oral evidence he had said that he knew of only two children with similar neurological conditions who had been transferred to home care but neither had had the same severe respiratory problems. At paragraph 53 he recorded:

> "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."

39. He concluded that Dr Wallis's assessment of a 25% chance of a successful transfer to long term ventilation at home was too optimistic, observing that it could not easily be reconciled with his observation that her condition was "at the absolute outer limits of what might be achievable at home." He expressed his conclusion on the chances of the transition succeeding in these terms (at paragraph 54):

> "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."

40. The judge then turned to consider the views of Pippa's family. He observed that no one is closer to Pippa than her mother and proceeded on the basis that she spoke for the entire family. At paragraph 56, he summarised the reasons for her view that it was in Pippa's best interests to continue to receive life-sustaining treatment:

> "(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."

41. In scrutinising these views, the judge recorded the mother's reasons for believing that there was a basis for some 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."

The judge recorded that none of the medical witnesses, including those on whose evidence the mother relied, believed it likely that Pippa will make any form of recovery. Dr Playfor advised the court that changes in Pippa's movements represented the neurological evolution and maturation of the underlying brain injury rather than any form of improvement in her condition. As for keeping her alive to allow her to enjoy the benefits of any developments in medical science, the judge observed (at paragraph 59):

> "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."

The judge then considered the views of the medical professionals on Pippa's best interests. He observed that the opinion of clinicians and medical experts on all matters touching on Pippa's best interests was "welcome because their experience in caring for very ill children gives them considerable insight". Although the views of all the medical witnesses on the non-medical aspects of best interests carry less weight than their views on medical matters, they should be taken into account.

42. Next, the judge considered briefly the child's ascertainable wishes, feelings values and beliefs. He noted that it was not possible to ascertain her current wishes and feelings, but took into account that before she lost capacity for conscious awareness she knew she had the unconditional love and dedication of her mother, brother and other family members. He added (at paragraph 68):

> "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."

43. The judge then turned to his analysis of Pippa's best interests. It is important to note that he conducted this analysis in two sections, the first (paragraphs 70 to 90) addressing

the option of continuation of long-term ventilation on the PICU and the second (paragraphs 91 to 108) considering the option of embarking on a trial of home ventilation.

44. Turning first to continuation of long-term ventilation on the PICU, the judge started by noting that, although the mother would prefer that outcome if the only alternative were withdrawal of ventilation, her counsel did not submit that it would be in Pippa's best interests. He recorded that he gave "considerable weight" to the preservation of life, but added:

> "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."

He recorded that the medical evidence "overwhelmingly" supported the conclusion that she was in a persistent vegetative state with no prospect of improvement. In circumstances in which

> "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"

he concluded that there was

> "no subjective benefit to Pippa from being kept alive on the PICU."

45. At paragraphs 75 to 77, the judge considered but rejected a submission made on behalf of the mother that by definition there is no physical harm caused by the provision of medical treatment to a person with no conscious awareness. He held that:

> "it would be an error to allow the absence of pain or 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."

His rejection of this submission forms the first ground of appeal to this Court and I shall consider the reasons for his decision below. Applying this approach to the circumstances of this case, he continued (at paragraph 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."

At paragraph 79, he continued:

> "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?"

I shall return to the judge's apparent distinction between "welfare" and "best interests" below.

46. At this point, the judge cited passages from MacDonald J's judgment the ***Raqeeb*** case, in particular paragraphs 172 and 176-7. He summarised a passage from the report of Dr Playfor (who had given evidence in ***Raqeeb***) and had subsequently changed his mind about rare cases of this type. In his report, Dr Playfor said:

> "5.18 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. With a tracheostomy and the provision of a portable mechanical ventilator, it should be possible, with considerable multi-disciplinary training and support, for Pippa to be cared for at home by her dedicated family in a manner consistent with values with which she has been raised. I note the observation of MacDonald J in [***Raqeeb***] that the prospect of being cared for at home is a relevant factor in determining the burden of indignity …."

47. In response to this evidence the judge commented:

> "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….
>
> 82. I 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."

48. At this point, the judge considered the role of "dignity" in the analysis of best interests. He observed (paragraph 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."

He disagreed, however, with Dr Playfor's revised views on this issue:

> "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."

49. He continued (at paragraph 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 …. There is a wide range of opinion as to what constitutes a dignified death …. 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."

50. The judge then returned to seeking to identify whether there were any benefits to Pippa from the prolongation of her life in the PICU:

> "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."

51. Drawing the threads together, the judge concluded that he was unable to find any benefit to Pippa from prolonging her life in the PICU. He took into account her mother's wish for Pippa to be kept alive, but "balancing all the relevant factors", he was satisfied (paragraph 90) that it was not in Pippa's best interests to continue to receive long-term ventilation or other life-sustaining treatment on the PICU.

> "Notwithstanding the presumption that life should be preserved, it is not in her best interests that her life should be prolonged…. 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. …. 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."

52. At paragraph 91, the judge then started his analysis of the option of embarking on the trial proposed by Dr Wallis. He took as his starting point his assessment that it was not in Pippa's best interests to continue with long-term ventilation on the PICU and asked what would be different about prolonging her life at home. He considered the mother's submission that such a course would be in her best interests because it would place her in her home environment surrounded by her loving family. Having set out the passages from the authorities cited to him by the mother's counsel on the weight to be attached to the views of a child's parents – *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502, *Re G* [2012] EWCA Civ 1233, and *Yates* – he concluded:

> "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."

53. He found on the evidence that a transfer to home care would not benefit Pippa's medical condition and that, as home care could never replicate the exceptional standards of PICU care, transfer home would, if anything, be a detriment to her. Furthermore, he was unable to discern any non-medical benefit to her welfare from her care being at home. He did not agree with the opinion of Dr Wallis and Dr Playfor that the benefits of family life at home changed the balance from withdrawing to continuing treatment. He acknowledged that there was a "clinical sterility" in the PICU and that it was a "busy

place with healthcare professionals constantly coming and going" and that, in contrast, "at home the environment would be more personal, perhaps more peaceful". Given the level of medical interventions and treatment that would still be required, however, her environment would in many ways be similar and "her home life would have many of the same features as life in PICU". In addition, he observed at paragraph 103(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."

54. He then set out his ultimate conclusion at paragraphs 104 to 107:

> "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….
>
> 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."

55. The judge therefore made declarations reflecting his conclusions, including that it was lawful and in Pippa's best interests for mechanical ventilation to be withdrawn. He added that the precise circumstances for that course were a matter for agreement but that it would not be contrary to her best interests to transfer her home for the purpose of withdrawal of ventilation, the Trust having indicated that extubation can be arranged to take place at home to be followed by appropriate palliative care.

The appeal

56. The appellant relies on four grounds of appeal.

(1) The judge erred in finding that medical treatment to prolong life constituted a physical harm to Pippa notwithstanding that she does not experience pain and has no conscious awareness.

(2) The judge erred in finding that there could be no non-medical benefit to Pippa by prolonging her life so that she could be cared for at home surrounded by her family due to her lack of awareness and young age.

(3) The court failed to give adequate weight to the views of Pippa's mother as to her best interests, in circumstances where her view was supported by reasonable body of medical opinion and Pippa did not experience pain from ongoing treatment.

(4) The judge's conclusion that it was not in Pippa's best interests to embark on a trial of portable ventilation was flawed for two reasons: (a) the court failed to analyse properly the prospects of success of a trial by failing to admit the evidence of Dr Chatwin that evidence given on behalf of the Trust was in some respects incorrect; (b) the court wrongly rejected the assessment of Dr Wallis that there was a significant chance of the trial of portable ventilation being successful and of Pippa being well enough to go home without making any finding about whether there were modifications to Pippa's regimen which had not yet been tried and which might improve the prospects of the trial succeeding.

Ground one

57. At paragraph 75 of his judgment, the judge recorded that it was a critical part of the mother's case that Pippa could not feel any pain and that her counsel had submitted that

> "by definition there is no physical harm caused by the provision of medical treatment to a person with no conscious awareness."

The judge, however, rejected this submission, and at paragraph 76 gave this explanation for doing so:

> "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."

58. At paragraph 77, he continued:

> "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 support of his approach, the judge cited observations of my Lady, King LJ, in *Re A (A Child)* [2016] EWCA Civ 759. In that case, this Court dismissed an appeal against a judge's declaration that it was lawful and in the best interests of a two-year-old child who had sustained catastrophic spinal cord and severe hypoxic brain injuries in a road accident to withdraw respiratory support and provide palliative care only. At paragraph 57, my Lady observed that in the evidence put before the judge at first instance there had been a disproportionate focus on the single issue of pain and a failure to stand back to consider the child's welfare "in its widest sense". The judge, however, had continued to maintain focus on the "overall picture" for the child, and my Lady endorsed her finding that

> "even if his life were 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."

59. On the present appeal, Mr Sachdeva and Ms Butler-Cole submitted that the judge's finding that Pippa could experience physical harm from medical treatment notwithstanding that she has no capacity to feel pain and no conscious awareness was wrong for three reasons. First, it was wrong in principle, since by definition no physical harm could be caused by medical treatment in such circumstances. Secondly, it was at odds with the approach taken by MacDonald J in *Raqeeb*. Thirdly, the judge was wrong to rely on the authorities from the law of tort cited in paragraph 76 of the judgment and had wrongly relied on my Lady's observations in *Re A*, which were addressing the different point whether the best interests test should focus on a single issue rather than the child's welfare as a whole.

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

the judge's reasoning for rejecting the appellant's proposition at paragraph 76 of his judgment.

61. The judge's approach is entirely consistent with the observations of my Lady in *Re A*. By focussing on the presence or absence of pain and failing to recognise the physical harm which an insensate patient may suffer from her condition or treatment, a decision-maker may fail to consider the child's welfare in its widest sense. Furthermore, so far as I can see, there is no support for the appellant's proposition to be derived from the judgment in *Raqeeb*. That case was decided on very different facts. Unlike Pippa, Tafida retained a minimal awareness, was in a stable condition, was not suffering life-threatening episodes of desaturations, and had received ventilation for a significantly shorter period. The level of support required by Tafida was not of the same degree of complexity and there was unanimity amongst all the doctors, including the treating clinicians, that she could be ventilated at home. Her condition and the treatments she received for it did not give rise to physical harm on the scale endured by Pippa in this case. In cross-examination, Dr Wallis acknowledged that the treatments given to Pippa were "on a spectrum of burdens". Furthermore, as demonstrated in the passages cited above from MacDonald J's judgment, the arguments advanced on behalf of the hospital trust in that case to the effect that it would be detrimental for Tafida to undergo the treatment proposed by her parents notwithstanding the fact that she could feel no pain were expressed in terms of dignity. In the present case, the Trust has not presented its arguments in those terms and the judge concluded that it would not assist him in this case to adopt any supposedly objective concept of dignity. In any event, it is worth noting that the argument presented to MacDonald J, as quoted in paragraph 176 of the judgment in *Raqeeb*,

> "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"

acknowledged that there would be "physical symptoms" which would be "debilitating" even though she could feel no pain.

62. The judge was entitled to conclude Pippa could experience physical harm from her condition and medical treatment notwithstanding that she has no capacity to feel pain and no conscious awareness. There is no merit in the contrary proposition advanced on behalf of the appellant. I would refuse permission to appeal in respect of the first ground of appeal.

Ground 2

63. The second ground of appeal is that, having concluded that he ought to take into account the detriment to Pippa's welfare caused by her condition and the treatment provided for it, the judge then wrongly went on to find that she could derive no value or benefit from prolonging treatment. Mr Sachdeva and Ms Butler-Cole submitted that the judge erred in proceeding on the basis that a young child with no awareness can experience the burdens of prolonging life through continued medical treatment but no benefits.

64. On behalf of the appellant, it was submitted, first, that the judge adopted an approach that was wrong in principle. It does not follow that a person's interests only relate to

pain or pleasure or only exist if the person has conscious awareness of them. As Baroness Hale said in the *Aintree* case, the decision-maker must look at welfare in its widest sense. In this case, it was common ground that Pippa has interests in the circumstances of her medical treatment and care even though she is not aware of them. Yet the judge concluded, at paragraph 88, that she could derive no palpable or impalpable benefit from prolonging her life. Secondly, it was contended that the judge's conclusion that there could be no benefit to Pippa from prolonging her life so that she could be cared for at home due to her lack of awareness was inconsistent with his earlier conclusion that he could consider the physical burdens of treatment notwithstanding her lack of awareness. Thirdly, it was said again that this approach is at odds with MacDonald J's judgment in *Raqeeb*.

65. The respondents do not accept the premise on which this ground of appeal is based. They contended that the judge did not conclude that there were no non-medical benefits to Pippa that were relevant to the assessment of whether it was in her best interests to undergo a trial of home ventilation. On behalf of the Trust, Mr Mylonas pointed out that the passages in the judgment on which the appellant relies as a basis for this second ground of appeal are found in the section of the judgment analysing whether it would be in Pippa's best interests to continue to receive long-term ventilation on the PICU, not in the subsequent section analysing whether it was in her best interests to embark on a trial of portable ventilation. When conducting the latter analysis, the judge carefully reassessed the benefits and burdens to Pippa by reference to the proposed trial before concluding that a trial was not in her best interests.

66. I have set out at some length the relevant parts of the judgment in which the judge analysed the two separate options – on the one hand, continuation of long-term ventilation in PICU and, on the other hand, a trial of portable ventilation. As already stated, the judge carefully structured his judgment by addressing these two options separately. Although there was plainly an overlap in the evidence, law and argument, the options were different and discrete, and each option required a different and discrete balancing exercise. The fact that the judge concluded (at paragraph 90) that he was unable to identify any non-medical benefits to Pippa from continued ventilation on the PICU ("whether social, emotional, psychological, or otherwise") did not mean that he necessarily concluded that there could be no such benefit to be derived from a trial of home ventilation. On the contrary, a careful scrutiny of the judgment (in particular paragraphs 105 and 106(d)) demonstrates that he concluded that there were potential non-medical benefits to be derived from such a trial, in particular that "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", but that they were outweighed by other factors. I do not accept the appellant's argument that the judge was saying that such benefits only arise if the patient has conscious awareness of them.

67. The appellant's submissions on this point elided discrete points made in the judge's separate analyses of the two options under consideration. With regard to the first option - continuation of ventilation on the PICU – the terms in which the judge framed the questions in paragraph 79 quoted above clearly demonstrate that he accepted that there could be non-medical benefits which should be considered as part of the best interests analysis. He concluded (at paragraphs 88 and 90) that on the facts of this case, having regard to the evidence and submissions presented to him, there was no such benefit for Pippa in continued care on the PICU.

68. With regard to the second option - the trial of portable ventilation leading to home care – in summarising what had been established by the close of the evidence about the proposed trial at paragraph 46, he recorded:

> “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.”

Having analysed the evidence, he found (at paragraph 104) that he was “not satisfied that home care would confer any benefits to Pippa’s welfare”. At paragraph 105, “looking at the wider question of whether home care, as opposed to PICU care, would serve Pippa's best interests”, he acknowledged that there were potential benefits, in particular that “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”. At paragraph 106, however, “standing back to consider and balance all welfare considerations and factors affecting best interests”, he concluded that long-term ventilation at home would be detrimental. Taking paragraphs 105 and 106 together, it is in my judgment plain that, in conducting that balancing exercise, the judge did take into account the non-medical benefits to be derived from living at home alongside arguments in favour of a trial but concluded that they were outweighed by the other factors which indicated that such a trial would be contrary to her best interests.

69. As noted above, at some points in the judgment the judge seemed to draw a distinction between “welfare” and “best interests”. In paragraph 78, 79 and 104, for example, he seems to regard “welfare” as a category or subset of “best interests”. During the hearing in this Court, counsel were unable to enlighten us as to how this distinction came to drawn. Looking back at the earlier reported authorities, I can find no basis for distinguishing between the two concepts. On the contrary, the case law demonstrates that the terms are normally used interchangeably.

70. In <u>*Re B (A Minor) (Wardship: Sterilisation)*</u> [1988] AC 199 at page 202, Lord Hailsham of St. Marylebone observed:

> “There is no doubt that, in the exercise of its wardship jurisdiction, the first and paramount consideration is the well being, welfare or interest (each expression occasionally used, but each, for this purpose, synonymous) of the … ward ….”

In <u>*Re F*</u> [1990] 2 AC 1 at page 54, Lord Brandon of Oakbrook observed that, when exercising its wardship jurisdiction, a court

> “would be bound to treat the welfare, or use an expression with substantially the same meaning, the best interests of the minor, as the paramount consideration”.

I have already cited paragraph 87 of this Court’s judgment in <u>*Wyatt v Portsmouth Hospital NHS Trust*</u> in which it was stated that:

> "The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount … The term "best interests" encompasses medical, emotional, and all other welfare issues."

In addition, as I have already mentioned, in the *Aintree* case, Baroness Hale said that:

> "in considering the best interests of this particular patient … decision-makers must look at his welfare in the widest sense."

My Lady adopted precisely the same approach in *Re A*, supra, a case involving the withdrawal of treatment from a child.

71. Accordingly, in considering applications concerning the withdrawal or continuation of life-sustaining treatment, no substantial distinction is to be drawn between the two concepts of welfare and best interests. I am entirely satisfied, however, that insofar as the judge purported to draw such a distinction at some points in his judgment, this did not undermine his ultimate conclusions. In expressing his conclusion about the continuation of long-term ventilation on the PICU, the judge said (at paragraph 90):

> "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."

Later, in expressing his ultimate conclusion on the proposed trial of home ventilation, the judge said (at paragraph 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 homecare is a feasible option."

72. Once again, I do not detect any material difference between the approach of the judge in this case to that adopted by MacDonald J in the *Raqeeb* case. The judicial approach to the balancing exercise was substantially the same in both cases, although the evidence adduced in each case and the outcomes which resulted from that evidence were significantly different.

73. Accordingly, whilst I would grant permission to appeal on the second ground, a careful reading of the judgment demonstrates that the judge did take into account the non-medical benefits to be derived from living at home. I would therefore dismiss this ground of appeal.

Ground 3

74. The third ground of appeal is that the court failed to give adequate weight to the views of Pippa's mother as to her best interests, in circumstances where her view was supported by a reasonable body of medical opinion and Pippa did not experience pain from ongoing treatment.

75. Mr Sachdeva and Ms Butler-Cole submitted that the correct approach to determining the weight to be attached to a parent's views when making a best interests evaluation was set out by Waite LJ in *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502 which, they say, was approved by this Court in *Yates* and followed by MacDonald J in *Raqeeb*. They acknowledged that the judge took the mother's views into account when considering both the option of continuation of long-term ventilation in the PICU and the option of a trial of ventilation at home. They submitted, however, that in conducting the latter balancing exercise, he gave insufficient weight to her view that the proposed trial was in Pippa's best interests and failed to explain his reasons. The mother's view was shared and supported by Dr Wallis and Dr Playfor, two highly reputable paediatricians with particular expertise in this field. In the light of those expert opinions, and the fact (as asserted on behalf of the appellant) that there were no medical burdens or benefits from ongoing treatment, the court's failure to accord proper weight to her view was inconsistent with the approach set out by Waite LJ in *Re T* and difficult to reconcile with that adopted by MacDonald J in *Raqeeb*.

76. In response, Mr Mylonas submitted that the approach to assessing the role of parental views in best interests cases is not controversial and is as set out by McFarlane LJ in *Yates*. He further submitted that the premise underlying the appellant's argument – that there are no medical burdens from ongoing treatment – was incorrect. He drew attention to the judge's detailed description of the mother's views at paragraphs 55 to 60 of the judgment, his consideration of the weight to be given to those views when considering the proposed trial of home ventilation at paragraphs 98 to 100, and his treatment of this factor in the ultimate balancing exercise at paragraph 106. It was submitted that, in carrying out this assessment, the judge acted entirely properly and in accordance with authority and that the appellant's assertion that the judge did not explain why so little weight was afforded to the mother's views was wrong. On behalf of the guardian, Mr Davy accepted that, where there is really nothing to choose between the benefits and detriments of the treatment options, a court may look to the parents to make that choice. In this case, however, proper application of the best interests test did not lead to a finely-balanced result between the benefits and burdens of long-term ventilation.

77. In support of this third ground of appeal, the appellant relied heavily on the dicta of Waite LJ in *Re T*. The circumstances of that case, however, were very different. It concerned a baby born with a life-threatening liver defect. The unanimous opinion of the medical consultants was that he should undergo a liver transplant. His parents, who were both healthcare professionals experienced in the care of sick children, disagreed. Shortly after birth the baby had undergone the surgery which had been unsuccessful and caused much pain and distress. Thereafter, the father obtained a post abroad and, against medical advice, the mother took the baby out of the country to visit him. Before Connell J, the local authority successfully obtained declarations that it was in the baby's best interests to have the transplant and for permission to perform the operation notwithstanding the mother's refusal to consent, and an order for the child to be returned to the jurisdiction for the purposes of surgery. This Court allowed the mother's appeal and set aside the declarations and order.

78. All three of the judges in this Court delivered judgments. In the course of her judgment (at page 510), Butler-Sloss LJ noted:

> "The welfare of this child depends upon his mother. The practical considerations of her ability to cope with supporting the

> child in the face of her belief that this course is not right for him, the requirement to return probably for a long period to this country, either to leave the father behind and lose his support or to require him to give up his present job and seek one in England were not put by the judge into the balance when he made his decision."

Although she noted the "very strong presumption in favour of a course of action which will prolong life", Butler-Sloss LJ (at page 512) stressed that

> "on the most unusual facts of this case with the enormous significance of the close attachment between the mother and baby, the court is not concerned with the reasonableness of the mother's refusal to consent but with the consequences of that refusal and whether it is in the best interests of C for this court in effect to direct the mother to take on this total commitment where she does not agree with the course proposed …. The prospect of forcing the devoted mother of this young baby to the consequences of this major invasive surgery lead me to the conclusion, after much anxious deliberation, that it is not in the best interests of this child to give consent and require him to return to England for the purpose of undergoing liver transplantation. I believe that the best interests of this child require that his future treatment should be left in the hands of his devoted parents."

79. This was the context in which Waite LJ in his judgment (at page 513-4) made the observations to which counsel for the appellant in this case attached particular weight:

> "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 certainty) that the greater the scope for genuine debate between one view and another the stronger will be 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."

80. In his judgment, Roch LJ made this observation:

> "The view of the parents in a liver transplant case has two aspects. First, if, as here, the parents are devoted and responsible and have the best interests of their child in mind, then their views are to be taken into account and accorded weight and respect by the court when reaching its decision. Secondly, the views of the parents have a clinical significance because in the absence of parental belief that a transplant is the right procedure for the child, the prospects of a successful outcome are diminished."

In the circumstances of that case, Roch LJ emphasised the "formidable practical difficulties" which stood in the way of implementing the judge's order.

81. It is clear from these citations that the circumstances of ***Re T*** were very different to those arising in the case with which we are concerned. It is important to bear in mind the caveat at the start of the passage from Waite LJ's judgment cited above – "all these cases depend on their own facts." In *Yates*, this Court was concerned with a factual matrix much closer to that of the present case – an application by a hospital trust for a declaration that it was lawful to withdraw artificial ventilation from a child. The parents opposed the application and proposed instead that the child should travel abroad for treatment, a course which the judge at first instance concluded on the evidence to be futile. In this Court, McFarlane LJ observed at paragraph 80:

> "Under the accepted approach to best interests cases the weight to be attached to the views of a child's parents may vary and, where there is real scope for debate as between two treatment options, the views of the parents may well be very important."

Having cited a number of authorities, including *Re T*, McFarlane LJ concluded:

> "94. …. Even if such a case may fall at the more favourable end of the spectrum described by Waite LJ, the court does not evaluate the reasonableness of the parents' case, or, as these authorities indicate, introduce any other factor or filter before it embarks upon deciding what is in the best interests of the child.
>
> 95. 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.
>
> 96. If one option is favoured by a parent, that may give it weight, or as Waite LJ put it, incline the court to be 'influenced by 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'. Notwithstanding that that is the case, in the end it is the judge who has to choose the best course for a child."

82. In supporting the dismissal of the parents' appeal, McFarlane LJ added (at paragraph 112):

> "It goes without saying that in many cases, all other things being equal, the views of the parents will be respected and are likely to be determinative. Very many cases involving children with these tragic conditions never come to court because a way forward is agreed as a result of mutual respect between the family members and the hospital, but it is well recognised that parents in the appalling position that these and other parents can find themselves may lose their objectivity and be willing to "try anything", even if, when viewed objectively, their preferred option is not in a child's best interests. As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

83. It is this authoritative statement by McFarlane LJ which encapsulates the approach to be adopted by courts deciding the weight to be attached to the views of a parent on an application for a declaration that it is lawful for life-sustaining treatment of a child to be withdrawn.

84. There may be cases in which the arguments are balanced in such a way that the views of a parent may be decisive. Waite LJ's dicta in *Re T* were cited by MacDonald J as part of his reasoning in *Raqeeb* when refusing the applicant NHS Trust's application for a declaration authorising the withdrawal of life-sustaining treatment. He found (at paragraph 182) that:

> "… in circumstances where Tafida is not in pain, where the burden of the treatment is low, where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to her being cared for at home on ventilation by her family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction, where there is a funded care plan to this end, where Tafida can be safely transported to Italy, where the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised and having regard to the sanctity of Tafida's life, this case *does* in my judgment lie towards the end of the scale where the court should give weight to the reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of the child's life will

> be taken for the child by a parent in the exercise of their parental responsibility."

85. The case with which we are dealing is very different. At the time of the hearing before MacDonald J, Tafida Raqeeb had received only seven months of ventilation. In contrast, by the time of the first hearing in the present case, Pippa has been ventilated for nearly two years. Unlike Pippa, Tafida was in a stable condition and not subject to the regular life-threatening episodes of desaturation. The degree of specialist support required by Pippa is on a significantly greater scale that that needed by Tafida. All the experts agreed that Tafida could be ventilated at home. In the present case, the treating team are firmly of the view that this is not feasible, and Dr Wallis, whilst believing that it may be achievable, accepts that it is at the "absolute outer limits" of what can be managed at home. The judge noted that he had "no reassurance that her envisaged package of home care is practically achievable." In contrast to the position in *Raqeeb*, there is currently no funded plan in the present case to support the proposal for home ventilation. Although some of the experts supported the proposal of a trial of portable ventilation with a view to a return to home care, none of the clinicians or experts thought that such a course would lead to any improvement in Pippa's medical condition and the judge found that the proposed trial would increase Pippa's burdens.

86. Nonetheless, at paragraphs 55 to 60 the judge set out the mother's views in considerable detail and manifestly took those views into consideration when analysing both the option of continuing ventilation in the PICU and the option of a trial of portable ventilation leading to home care. In my judgment, the weight he attached to the mother's views was carefully calibrated and justified on the evidence. I do not agree that he failed to provide a sufficient explanation for his reasons for not adopting the course proposed by the mother or for the weight he attached to her views. His analysis in paragraphs 91 to 108 is a comprehensive assessment and provides a clear explanation of the reasoning behind his decision. He took into account the fact that the mother's view was supported by Dr Wallis and Dr Playfor, although he did not attach weight to her view that home care would improve Pippa's condition because, as he explained at paragraph 106(e), that view was contrary to the unanimous opinion of the clinicians and medical experts. Unlike *Raqeeb*, this was not a case that fell within the category identified by Waite LJ in *Re T* where there is "genuine scope for a difference of view between parent and judge" and "an expectation that difficult decisions affecting the length and quality of [the child's] life will be taken for [her] by the parent to whom [her] care has been entrusted by nature." Rather, it was a case in which the judge properly followed the "sole principle" identified by McFarlane LJ in *Yates* that "the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view".

87. For these reasons, I would refuse permission to appeal on the third ground.

Ground 4

88. Finally, the appellant argues that the judge's conclusion that it was not in Pippa's best interests to embark on a trial of portable ventilation was flawed for two reasons. First, it is said that the court failed to analyse properly the prospects of the success of a trial by failing to admit the evidence of Dr Chatwin that evidence given on behalf of the Trust was in some respects incorrect. Secondly, it is argued that the court wrongly rejected the assessment of Dr Wallis that there was a significant chance of the trial

succeeding without making any finding about whether there were modifications to Pippa's regimen which had not yet been tried and which might improve the prospects of the trial succeeding.

89. The evidence of Dr Chatwin to which this submission is addressed was contained in a supplemental report dated 22 December 2020, four days after the hearing. In the report, the fourth that she had prepared in the proceedings, Dr Chatwin stated that, contrary to evidence given by Ms F in response to Dr Wallis's oral evidence, Pippa's medical records revealed no evidence to support the assertion that her oxygen saturation was being kept at 98 to 100% for the majority of the time. It was submitted on behalf of the appellant that the judge's decision to disregard the report revealed a failure to understand the relevance of Dr Wallis's evidence of the possible modifications to Pippa's regime. As to that evidence, it is submitted that the proposed modification was central to Dr Wallis's opinion about the prospects and that the judge therefore erred in law by failing to make detailed findings about whether those modifications were possible.

90. Mr Mylonas submitted that there is no merit in either of the complaints raised under this ground of appeal. He pointed out that Pippa's ventilatory status and her respiratory instability had been central features throughout the proceedings on which the served expert evidence was focused. Notwithstanding the extensive consideration given to those features in the expert discussions prior to the hearing, it was only during Dr Wallis's oral evidence that he raised a number of further suggestions, none of which arose out of any change or development in Pippa's condition. Had any of his points been raised earlier, the Trust could and would have responded in writing, just as it had responded to Dr Wallis's earlier suggestions about the proposed trial of portable ventilation and a tracheostomy. In the circumstances, the judge's criticism at paragraph 44 of the judgment of the way Dr Wallis had introduced these suggestions was entirely justified. Notwithstanding that criticism, the judge (at paragraphs 51 and 52 of the judgment) duly considered Dr Wallis's evidence, including the additional proposed modifications to the treatment programme raised belatedly in his oral evidence, before reaching his decision. As Mr Davy pointed out, the judge (at paragraph 51(d)) accepted that "there may be several adjustments that could be made to optimise the chances of success of the trial and transition".

91. With regard to Dr Chatwin's fourth report Mr Mylonas reminded us of the very recent observation of Peter Jackson LJ in *Z, M, S, R v RS and University Hospitals Plymouth NHS Trust* [2021] EWCA Civ 22 when, in giving reasons for dismissing an appeal against a judge's refusal to allow the instruction of a further expert at paragraphs 20 and 22, he said:

> "Part 15 of the Court of Protection Rules 2017 provides that the court has the power to control the introduction of expert evidence and is under a duty to restrict expert evidence to what is necessary to assist the court to resolve the issues in the proceedings. A court-sanctioned expert has an overriding duty to the court. Respect for the procedural rules is of particular importance when the proceedings are of gravity. In the present case, the Court made appropriate directions for independent expert evidence …. These are not rolling proceedings which a dissatisfied party can continue at will. Far from there being any

> unfairness in the refusal to permit the instruction of a further unidentified expert, there is in my view a real risk of harm to the protected party and of unfairness to other parties if litigation is conducted in such an unprincipled way."

92. In the present case, four days after the conclusion of the hearing, the appellant's solicitor filed and served a fourth report from Dr Chatwin without notice and without the court's permission. Mr Mylonas submitted that this was an attempt to roll out new evidence in support of the appellant's case after the evidence had closed in precisely the manner deprecated by Peter Jackson LJ. It was submitted that this was particularly unfair to the Trust because the points addressed in the report had only been provided orally by the Trust in response to the matters raised for the first time by Dr Wallis in his oral evidence. In the circumstances, the judge was fully entitled in the exercise of his case management powers to refuse to admit the report.

93. Mr Davy draws attention to an email sent by the judge via his clerk to the parties on 23 December 2020 setting out his reasons for refusing to admit the report. In that email, included in the supplementary bundle for this appeal, the judge, having reminded himself of the overriding objective, stated *inter alia*:

> "The issues addressed by Dr Chatwin in this fourth report concern adjustments to Pippa's management which might affect a transition to home care, and whether and to what extent they have already been attempted or made. I have already received evidence from witnesses called by both the applicant and the second respondent in relation to those adjustments and the overall likelihood of transition being achieved. I have sufficient evidence on these matters to enable me determine the issues in this case, and to do so fairly …. It would be disproportionate to admit the evidence: to do so would lead to yet further evidence being adduced in response …. The issues addressed by Dr Chatwin in this fourth report are not, in my judgment, at all central to … the obviously very important issues that the court must determine."

Mr Davy submitted that, given the judge's conclusion that the chances of success of both a trial of portable ventilation followed by a transition process were remote and that long-term ventilation at home would be contrary to Pippa's best interests, the content of Dr Chatwin's fourth report was of no consequence to the judge's decision.

94. On this fourth ground of appeal, I again accept the submissions made on behalf of the respondents. I do not agree with the appellant's submission that the judge failed to grapple with the medical and expert evidence and to give reasons for departing from Dr Wallis's opinion. He clearly took into account Dr Wallis's oral evidence about potential modifications to the treatment programme, notwithstanding the unsatisfactory way in which that evidence had been adduced. Contrary to the assertion in the appellant's submissions, the judge acknowledged that there were modifications suggested by Dr Wallis which might affect the trial and transition plan but concluded on the basis of the totality of the evidence that the proposal was not in Pippa's best interests. The fact that he did not set out in full detail Dr Wallis's evidence about the proposed modifications does not mean that he failed to take that evidence into account.

95. As for Dr Chatwin’s fourth report, the judge’s decision to refuse to admit the report, as explained in his email dated 23 December 2020 and summarised in paragraph 44 of his judgment, was plainly within his case management powers and consistent with the principles in the court rules. In any event, he was entitled to conclude that the issue addressed in the report was not central to the evaluation of Pippa’s best interests and the merits of the proposed trial of portable ventilation.

96. I would therefore refuse permission to appeal on the fourth ground.

97. Thus far, I have not considered the concept of dignity which featured in a number of the earlier judgments, including that of MacDonald J in *Raqeeb*. Although it was mentioned in the course of the judgment in this case, it was not a factor which the judge included as a reason for his decision.

98. On behalf of the appellant, Mr Sachdeva observed in oral submissions that dignity was not, as he put it, the touchstone. In his submissions on behalf of the guardian, however, Mr Davy made extensive submissions about the concept of dignity and its role in decisions concerning the withdrawal of life-sustaining treatment. It was his contention that, in addition to the principle of the sanctity of life and principle of self-determination, the court in these circumstances should take into account the principle of the respect for the dignity of the individual. He submitted that the judge was correct to identify amongst the factors relevant to his decision both the burdens arising from the intensive and intrusive treatment required to keep Pippa alive and her grave loss of function and the potential benefits to be gained from treating her at home surrounded by her loving family rather than in hospital. Mr Davy submitted, however, that the real justification for including these burdens and benefits is that they are both aspects of the principle of respect for the dignity of the individual. He argued that this principle requires respect for an individual’s value as a human being and encompasses both their psychological and physical integrity being deemed worthy of respect. Somebody who has no awareness of their circumstances can still be afforded dignity, or treated with indignity, by the manner in which they live and the way in which they are treated. Mr Davy submitted that, in Pippa’s case, there is an innate indignity and burden associated with the intensive and intrusive treatment required to keep Pippa alive and her grave loss of function. Alternatively, if she were able to be cared for at home surrounded by her loving family, this would be a less undignified existence than her current care within the PICU. Notwithstanding these submissions, however, the guardian concluded that, when all the factors relevant to the decision are taken into account including the three principles of sanctity of life, self-determination and respect for the dignity of the individual, the potential benefit to Pippa from being cared for at home did not come close to tipping the best interests balance.

99. Mr Davy developed these arguments by reference to a number of reported authorities, in particular the decision of the House of Lords in *Airedale NHS Trust v Bland* [1993] AC 789. I commend him for the thought and care with which he has prepared those submissions and I intend no disrespect to him in saying that I do not think it necessary or appropriate on this occasion to embark upon a detailed analysis of the arguments he deployed. The judge declined to attach any weight to the concept of dignity in reaching a decision about Pippa’s best interests, observing (at paragraph 86):

> “there is obviously a high degree of subjectivity involved in describing someone’s life or death as having dignity”

and cited authorities in which the protection of dignity had been deployed to support decisions both to continue treatment and to withhold it. He concluded:

> "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."

Neither the appellant nor the Trust has sought to argue that he was wrong in adopting that course.

100. Other judges, dealing with cases involving different circumstances, have taken a different approach: see for example MacDonald J's decision in *Raqeeb*. In a future case, it may be necessary for this Court to address arguments akin to those put forward by Mr Davy about the role played by the concept of dignity in decisions of this sort. That necessity does not arise on this appeal.

101. Every parent dreads the prospect of their child contracting a terminal illness. No parent could have done more than Pippa's mother to care for her child or fight for her future. As the judge observed at the end of his judgment, however, in this case the law vests responsibility for decisions in the court, not the parent. I am entirely satisfied that the judge was entitled to conclude and declare that it was lawful and in Pippa's best interests that life-sustaining treatment be withdrawn for the reasons he gave in his judgment.

ELISABETH LAING LJ

102. I agree.

KING LJ

103. I also agree.