This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Neutral Citation number: [2021] EWHC 2574 (Fam)

Case No: FD21P00404

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
IN THE MATTER OF THE INHERENT JURISDICTION
IN THE MATTER OF ABC (d.o.b. January 2020)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22/09/2021

Before :

MR JUSTICE PEEL

- -

Between :

(1) GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST
(2) NORTH WEST LONDON UNIVERSITY HEALTHCARE NHS TRUST

Applicant

- and -

(1) MBC
(2) FBC
(3) ABC (through her Children's Guardian)

Respondents

- -
- -

Michael Mylonas QC (instructed by **Hill Dickinson LLP and Capsticks LLP**) for the Applicant
Emma Sutton for the First Respondent
Neil Davy and Susanna Rickard for the Second Respondent
Shabana Jaffar (**Cafcass Legal**) for the Third Respondent

Hearing dates: 14-17 September 2021

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Approved Judgment

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

....

Mr Justice Peel :

1. ABC was born in January 2020 and is therefore 19 months old. She is the much-loved child of devoted parents, and equally dearly loved by her 4-year-old sister.

2. ABC was born after an emergency caesarean section following fetal bradycardia. She had APGAR scores of 0, 0 and 3 at 1, 5 and 10 minutes. She underwent resuscitation for 7 minutes until a heartbeat was detected. She was given adrenaline and chest compressions. She was intubated, ventilated, and actively cooled. At 2 hours of life she had convulsive seizures, lip smacking and jaw jerking which are indicative of ischaemic brain injury. At 5 days old she underwent an MRI scan which revealed catastrophic damage to multiple areas of the brain. The treating team suggested withdrawing the life sustaining treatment, but the parents did not agree; this indicates both what the clinicians foresaw for ABC's life ahead, and also the parents' determination to do everything possible for their daughter. ABC started to trigger spontaneous breaths and, upon being removed from her ventilator at day 14, was able to breathe with high flow oxygen. She was transferred to the hospital local to her home, Northwick Park. She was weaned off high flow oxygen, and since 28 days of life has been able to self-ventilate at least for periods of her life.

3. Tragically, the result has been catastrophic destruction of the brain with profound and lifelong neurological injury. She has whole body dystonic cerebral palsy, and global profound developmental impairment. She is uncommunicative. The injury to her brain is not progressive, but nor is there any possibility of recovery or improvement. In short, there is no cure. Her life expectancy is, at best, to late teens/early adulthood.

4. At 28 days after birth, she was discharged home where she has been ever since, apart from time spent at hospital during repeated emergency admissions. Her primary hospital is Northwick Park, from where she has been regularly referred to Great Ormond Street Hospital.

5. She is wholly dependent and has a number of carers within a 120-hour care package to assist with her complex needs including medication, suctioning, feeding and bathing. To stay alive requires life sustaining intervention and high levels of medical care.

6. At home, ABC has her own specialist bed and medical equipment. She is continuously connected to (i) a machine and oxygen cylinder controlling her nasopharyngeal airway and (ii) a machine feeding her via a peg-J feeding tube. She requires suctioning several times an hour every day, mouthcare, and repositioning to ensure her stoma does not become infected. ABC does not currently need ventilation during her baseline state. She maintains her oxygen saturations with nasal cannula oxygen. She is treated with 5 drugs for dystonia, 1 for seizures, 2 for secretions and one for her reflex. She is, therefore, subject to a very wide range of interventions.

7. ABC periodically requires hospital admissions for dystonic crises, infections and/or respiratory issues, particularly chest infections due to secretions collecting in her lungs. In total there were 11 admissions to Great Ormond Street Hospital, via Northwick Park Hospital, between birth and 17 June 2021, totalling 30 weeks. Since 9 November 2020, when she received a botox injection to reduce secretions, and the insertion of a nasopharyngeal airway on 7 January 2021, the number of admissions has reduced.

From 9 November 2020 to June 2021, she did not require invasive ventilation. In other words, the dystonia is now better controlled and the frequency of admission for invasive ventilation is reduced. There were 3 admissions in June and July of this year, each lasting about 24 hours, all of which required intubation and invasive ventilation, although Dr S thought they might perhaps have been capable of treatment with non-invasive ventilation.

8. ABC has a very poor quality of life with extremely painful dystonia and spasticity. There is no cure. She is permanently wheelchair bound, unable to speak or, in my judgment, have meaningful social interactions, and demonstrates negligible visual or auditory awareness. When she is awake, she experiences, according to the medical evidence which I accept, considerable and constant pain. When she has dystonic episodes at home, the pain increases to an excruciating level. There is no visible sign of pleasure in her life. The nursing team describes the pain and discomfort that ABC demonstrates and the lack of any joy. She is at the most severe end of the spectrum. At best, she experiences some occasional reduction in pain and discomfort. She has no purposeful movements of her limbs. She cannot communicate. She experiences whole body motor disorder, epilepsy, gastroesophageal reflux, chronic lung disease and an inability to swallow, feed or manage secretions. The experience of having secretions was described to me by Dr M as being “like drowning” for her. He told the Guardian that “I really feel I have tortured this child a lot” with repeated painful medical interventions offering no improvement, and prolongation of suffering.

9. ABC’s life expectancy is reduced, and her condition will remain unchanged. Her prognosis is for repeated infections, respiratory crises, seizures, contractures, the risk of pressure sores and bodily deformity. The doctors, particularly Dr M, told me that there are likely to be more frequent admissions in the future, largely caused by changes to her skeleton as she grows, including increased curvature of the spine which will weaken respiratory functioning, and weakening of the lungs.

10. ABC’s lack of ability to communicate in itself exposes her to the potential of harm. As an example, on one occasion while in the bath under the supervision of a carer she sustained a fractured femur. She was unable to communicate her pain and it took some time before the fracture was detected and treated, during which time she is likely to have experienced considerable suffering.

11. The sad reality of this case is that most of the medical interventions since birth have been directed at prolonging life, with no possibility of improving its quality. Mitigation of pain and discomfort is the best that can be achieved.

The family composition

12. ABC’s mother (“M”) works part time and is taking a vocational degree. ABC’s father (“F”) is in full time employment. They are married. ABC lives with her parents and sister in London. M is, in practice, ABC’s primary carer. The family are practising Muslims. F in particular holds profound religious views, rooted in his respect for the Quran. It is beyond doubt, remarked upon by the treating clinicians and the Guardian, and shining through from the evidence of the parents, that ABC is deeply loved and receives the highest quality of care and attention from her parents. They are totally motivated to do what is best for her. ABC is an equal member of the family unit. The

affection, love and joy felt by ABC's family towards her is palpable. I have seen moving photographs and video clips which, whilst being only momentary insights into family life, bear witness to the strength and unity of the family. The Guardian describes them as doting and thoughtful parents. Having seen and heard from both parents, I wholeheartedly agree.

The applications and the parties' positions

13. The applicants jointly apply for the following:

    i) declarations that it is not in ABC's best interests to receive:

        a) Any invasive forms of ventilation including long term ventilation by tracheostomy;
        b) Escalation of intensive care support in the form of vasoactive medication or renal replacement therapy ("RRT");
        c) Cardiopulmonary resuscitation ("CPR").

    ii) Declarations that it is in ABC's best interests to continue to receive

        a) Non-invasive ventilation including CPAP, BiPAP, Opti-flow and masked ventilation;
        b) Intubation – if the treating clinicians consider it appropriate and only where it is provided to improve her quality of life (e.g if she needs replacement of feeding tube) rather than in progression of underlying disease.

14. It is the applicants' case that continuing to administer aggressive and invasive forms of treatment (particularly respiratory) is not in line with ABC's best interests. They acknowledge that the proposed ceiling of care, limited to non-invasive ventilation, would likely (although not certainly) result in shortening of her life. The proposed care plan is for pain medication and sedatives in the event non-invasive ventilation is insufficient to meet her breathing requirements, thereby ensuring that her death is as comfortable, pain free and peaceful as possible.

15. M understands the pain, and life limiting restrictions, experienced by ABC. She does not feel that ABC's life should be prolonged at all costs, acknowledging that the suffering felt by ABC may outweigh what little benefit she receives from her life. She considers that the current cycle of emergency hospital admissions should not continue. Her dilemma, which is shared by all the parties and the court, is that she does not want ABC to die, nor does she want her to continue to live like this.

16. She is of the view that a ceiling of care is necessary and does not oppose the applications. At the outset of the hearing, she wished consideration to be given to a long-term tracheostomy in the hope that this would remove the cycle of repeated intubations when she has difficulty breathing. Having heard the evidence, I was informed during the hearing that she did not oppose the withholding of long-term tracheostomy, as sought by the applicants.

17. F, by the end of the hearing did not oppose the applications save for the vital words "Any invasive forms of ventilation". Thus, the critical issue in the case by its conclusion had narrowed to one aspect of the relief sought, namely whether withholding of invasive ventilation should be authorised. F puts forward a number of reasons for seeking the continued clinical option of invasive ventilation:

    i) The principle of the sanctity of life which needs no further elaboration by me save to say that, as F acknowledges, it is not an absolute principle and can be outweighed by other factors pointing in a different direction;
    ii) The principle of self-determination. F is confident that ABC would have been brought up in the Islamic faith and followed its tenets. He accepts that, given her age and medical condition, it is not possible to determine ABC's views from a religious perspective. But in a wider, non-religious context he submits that, from ABC's point of view, she would be likely to want to receive the love and comfort of her own family at home;
    iii) The parents' Article 8 and Article 9 rights should be taken into account, particularly if the decision is finely balanced;
    iv) The views of the doctors focus more on the medical benefits of the proposed ceiling of care, and less on the wider emotional, social, and psychological benefits;
    v) ABC currently experiences a high degree of burden in her life which has been deemed to be at an acceptable level, in the sense that no court authorisation to the contrary has been sought. That baseline, F submits, should be viewed as the starting point.
    vi) The key issue, therefore, on F's case, is whether the <u>additional</u> benefits and burdens above a non-invasive ventilation threshold would be in ABC's best interests. To that he says:
        - The number of invasive ventilations required reduced after November 2020, although there were 3 such episodes in June and July 2021 requiring intubation and invasive ventilation. For the most part, ABC can be treated with non-invasive ventilation.
        - If Northwick Park is able to treat with CPAP (as now appears to be the case), it should be possible to further minimise the number of admissions requiring invasive ventilation.
        - On the rare occasions where invasive ventilation would be required (his counsel posited once or twice per year, although acknowledging that there is a degree of speculation), it would be in her best interests to receive such treatment. The periods of invasive ventilation would likely be short (24 hours was posited, although again there was a degree of speculation), and, accordingly, invasive ventilation does not represent a significantly increased burden over and above (i) ABC's ongoing burden caused by her condition, including associated pain, and (ii) the already very high level of intervention.
        - Such a marginal increase in burden is outweighed by the discernible benefits in ABC's life.
    vii) F does not fully agree with the medical evidence assessment of the benefits to ABC of her life, pointing out that the clinicians generally see her in hospital during acute episodes. He says that at home, ABC is generally comfortable. She has some ability to see and hear and is soothed by the touch of her mother. She spends time outside in the fresh air. She is surrounded by loving family

members. In short, he considers that the benefits to ABC in her life, notwithstanding that she has minimal awareness, are understated, and outweigh the burdens

18. In his narrative statement, F sets out at some length his profound religious views which he says prohibit him from consenting to a ceiling of care which will shorten her life. He strongly adheres to the sanctity of life, having consulted a number of Imams whose teaching and guidance has informed his views. ABC's life is sacred and should be protected and preserved within human and medical capability, such that to withhold treatment potentially of benefit would be sinful. In his oral evidence to me, much less emphasis was placed by F on this aspect of the case. The position statement on his behalf acknowledges that his own deeply held religious beliefs do not constitute a free-standing factor to which discrete weight should be attached. However, F submits that an assessment of ABC's best interests must be informed by consideration of the religious beliefs of her family.

19. F told me through counsel that he regards this as a finely balanced decision. He comes down on the side of retaining the option of invasive ventilation. He understands why M does not.

20. ABC's Guardian supports the joint applications. She says that, if the medical evidence is accepted by me, the inevitable conclusion is that invasive ventilation would increase to a significant degree ABC's pain and suffering. It would not improve her quality of life in any way. It would serve only to prolong a life which is severely limited and from which ABC appears to derive at best negligible benefit.

Representation

21. All parties have been represented by counsel, to whom I am grateful for their clear and able written and oral submissions, as well as their immense courtesy towards all the witnesses, and their sensitive handling of difficult human issues. I would like to acknowledge in particular Ms Sutton, on behalf of M, and Mr Davy and Ms Rickard on behalf of F, who have acted pro bono, dedicating a great deal of time, energy and commitment to these intensely personal and demanding proceedings.

22. I cannot forbear from comment that it seems to me to be little short of scandalous that in cases of serious, and often urgent, medical treatment for children, where issues of life and death are frequently considered, parents such as these have little option but to rely upon the goodwill, availability, and dedication of members of the Bar acting for free.

The Law

23. There is no dispute on the legal principles to be applied. The parties agree that they are encapsulated by MacDonald J in **Manchester University NHS Foundation Trust v Fixsler [2021] EWHC 1426 (Fam).** I note that this decision was upheld by the Court of Appeal in **Fixsler v Manchester University NHS Foundation Trust [2021] EWCA Civ 1018** and no part of MacDonald J's following analysis of the law was disapproved:

> 56. The court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place, on the grounds that it is in the child's

best interests (see *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement between those with parental responsibility for the child and those treating the child (*An NHS Trust v MB* [2006] EWHC 507 (Fam)). The court has no power to require doctors to carry out a medical procedure against their own professional judgment.

57. As I have observed in previous cases, the legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not '*Gillick*' competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.
ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.
iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

"This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."

iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.
v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.
vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.
viii) Each case is fact specific and will turn entirely on the facts of the particular case.
ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may,

understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

"The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

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

58. These principles have been reiterated repeatedly at appellate level. In *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:
"[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

And

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

59. In the case of *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ again reiterated that:
"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

67. The difficult issue of the role of subjective or value laden ethical, moral or religious factors extrinsic to the child in the best interests decision was most recently considered by Poole J in *Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight [2021] EWHC 25 (Fam)* and by the Court of Appeal in the subsequent appeal in *Paula Parfitt v Guy's and*

St Thomas' Children's NHS Foundation Trust and Pippa Knight [2021] EWCA Civ 362 …..

69. ……… The task of the court is to identify what is in the subject child's best interests. It is well established that the concept of best interests is used in its *widest* sense and will include every kind of consideration capable of bearing on the decision and not limited to, medical, emotional, sensory and instinctive considerations.

70. Within this context, the judgment of this court in *Raqeeb v Barts NHS Foundation Trust and others [2020] 3 All ER 663* sought to recognise that some of the wide range of considerations relevant to the evaluation of best interests, such as the role of religious belief, futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, will be ones that admit, as the best interests principle itself can admit, of more than one "right" answer capable of driving the best interests decision of the court, particularly in the absence of factors which tend to attract societal consensus, such as the undesirability of pain and suffering. However, and consistent with the long-established process of evaluation conducted by the court with respect to best interests, whether, in a given case, those more subjective or value laden factors will drive the best interests decision will depend on the *totality* of the welfare factors that fall to be considered in that case.

73. In addition to the case law I have set out above, the guidance issued by the Royal College of Paediatrics and Child Health entitled '*Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice'*, published in March 2015 is of assistance in navigating the question of the child's best interests in these most difficult of cases. With respect to the issues raised in this case, the Guidance states as follows with respect to the sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, as treatments cannot provide overall benefit:

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

II When life is limited in quality
This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:
A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits;
B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life;
C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life."

74. In respect of circumstances where life may be of limited quality due to a lack of ability to benefit from continued life, the Guidance provides further illumination as follows:

"C. Lack of ability to derive benefit

> In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation. Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress."

24. To the above I would add the need to balance the relevant human rights considerations of both ABC and her parents, which seem to me to be Article 2 ("the right to life"), Article 8 ("Right to respect for private and family life) and, in the light of F's religious views, Article 9 ("Freedom of thought, conscience and religion").

The medical evidence

25. I heard oral evidence from a number of members of the treating team:

    i) Dr M, paediatric neurologist;
    ii) Dr S, paediatric intensivist;
    iii) Dr B, paediatric neurologist;
    iv) The ward manager;
    v) Dr E, paediatric consultant.

    These witnesses see and treat some of the sickest children in the country on a daily basis. I unhesitatingly accept their evidence. All were patently fair, balanced, and honest in their evidence. I was struck by the obvious, and committed, care they have all demonstrated for ABC, their affection for her, their wish to assist and comfort her where possible, and their wish to avoid prolongation of suffering where possible. Their dedication was palpable. Notably, many of them remained in court for the duration of the hearing even after giving evidence, such is their level of commitment to, and concern for, this child. They have had numerous, and lengthy meetings with the parents over a long period of time, and know them well. They seemed to me to have a good understanding of the parental views. I do not consider that they purely approached the best interests analysis from a medical point of view. In my judgment, they all have carefully taken into account the wider emotional, ethical, human, social, familial, environmental and psychological factors which presented to them. I propose to deal with their evidence in the analysis and conclusions section of this judgment.

26. The applicants obtained second opinions from the following:

    i) Dr H, professor of paediatrics;

ii) Dr H, consultant paediatric neurologist;
iii) Dr C, PICU consultant.

None of these were Part 25 appointed experts, nor did I hear oral evidence from them. I have, however, read their reports and note that they generally agree with the reports and conclusions of the treating clinicians

The parents

27. Both M and F were dignified, sensitive and measured in their evidence. I pay tribute to them both for their devotion and commitment to ABC.

28. Neither particularly challenged the medical evidence, although F in particular had a slightly different interpretation of some aspects. He accepted that ABC has an underlying discomfort caused by her dystonia, but found it difficult to accept the description by Dr M of the base discomfort level as "very painful". Further, contrary to the medical evidence, he considers the dystonic episodes experienced at home (which last up to 15 seconds) to be part of that general underlying dystonia, rather than intense crises, and thereby part of the general discomfort, rather than precipitative of what Dr M described to me as "excruciating" pain. To his mind, crises (and associated acute pain) are prolonged episodes, perhaps lasting 20 minutes or so, which occurred in the early months before November 2020. Since then, he told me (and the evidence supports this) that her dystonia has been better managed. He therefore finds it difficult to categorise the levels of pain in the way expressed by Dr M.

29. Both parents consider that ABC is at times responsive and has some awareness; F was more emphatic on the point than M. Both point particularly to the reassurance and comfort apparently felt by ABC on being touched by M. They both consider that there is some visual and auditory responsiveness, although I formed the clear view that F relied more on these aspects than M, who was more influenced by the reaction to touch. Both told me that ABC appears to respond to music, nursery rhymes and recitations of the Quran, and watching cartoons on her iPad. F produced 3 videoclips purporting to show ABC (in two of them) responding to his voice and fixing her gaze on him, and (in one) vocalising with headphones. F says that ABC appears to respond to him speaking to her "4-5 times out of 10", by following him with her gaze. She experiences dystonic episodes at home (e.g. when a nappy is changed) but these can be treated by rescue medication and F describes them as "manageable". Neither parent went so far as to say that any such responses (touch, sight, or hearing) amounted to joy or pleasure in ABC.

30. F was much less influenced by his religious beliefs in his oral evidence than appeared from his written statement. He told me that he would adopt the same opposition to the invasive ventilation application even if he had no faith-based reason to do so. He is influenced more by what he believes are the benefits from life enjoyed by ABC. That said, I sensed from him that his lack of certainty about precisely what ABC experiences leads him to rely on his own faith and hope; he told me that "I can only hope there is some joy".

31. F firmly believes that future admissions requiring invasive ventilation are likely to be rare, because of the success in the past 10 months in managing the dystonia. He believes that invasive ventilation should continue to be available. He told me that had he been

asked the question before November 2020, he might very well at that time not have opposed the declarations now sought, but the stability of ABC, his increased belief that she has some degree of sight and hearing, and the reduced number of admissions since then, satisfies him that it is right to continue on the current path.

32. M, by contrast, has come to the conclusion that the current cycle cannot continue. She considers that any invasive ventilation would not be in ABC's interests. When it was put to her on behalf of F that invasive ventilation, perhaps once or twice a year, would be rare, and thereby a minimal burden as against the benefit to ABC of the rest of the year, she replied pithily that in her view admission once or twice a year is not rare. She does not want ABC to experience that level of pain again.

The Guardian

33. The Guardian has met and spent time with ABC twice, once at her home and once during a hospital admission. She has spoken to the parents, together and separately, and other family members. On meeting ABC at home, the Guardian felt that her gaze was unfixed and not focused on anything in particular. She appeared to be in distress, with laboured breathing and intermittent sounds of discomfort during a period of about 3 ½ hours. At hospital, ABC seemed notably more peaceful and relaxed with her breathing being assisted. The Guardian could detect no indication of engagement with, let alone pleasure derived from, her surroundings.

34. The Guardian's report is notably insightful, empathetic, child focused and balanced. She said that she could not praise the parents enough for how they have cooperated with her. Her analysis is particularly thoughtful. She says that ABC should not have to experience any further pain or suffering. Any further admissions requiring invasive ventilation would be firmly contrary to ABC's interests. She would endure pain and suffering, and there would be no impact on ABC's quality of life. She told me that having heard all the evidence, her conclusion in her report to support the applications was strengthened.

Analysis and conclusions

35. I turn now to consider my assessment of the evidence and analysis of the case. Although I deal with this under a number of sub-headings, I have not compartmentalised the evidence, but have taken it into account holistically guided throughout by the best interests of ABC. In short, I have looked at the totality of the evidence. Albeit in a different context the dicta of Dame Elizabeth Butler-Sloss P in **Re T [2004] EWCA Civ 558, [2004] 2 FLR 838** at 33 resonates:

> "Evidence cannot be evaluated and assessed in separate compartments. A judge in these difficult cases must have regard to the relevance of each piece of evidence to other evidence and to exercise an overview of the totality of the evidence……"

Non-invasive and invasive ventilation, and the ability of the hospitals to provide such treatment

36. Non-invasive ventilation can be provided in a number of different ways, including:

    i) High flow nasal cannula oxygen ("HFNC");

ii) Continuous positive airway pressure ("CPAP");
iii) Bi-level positive airway pressure ("BiPAP"). This is provided in two phases, with higher pressure when breathing in and lower pressure when breathing out. It therefore has to be synchronised with the patient's breathing.

37. Northwick Park can provide ABC with HFNC. BiPAP is not usually provided in emergency departments, and is not available at Northwick Park. CPAP at Northwick Park is not usually provided for patients over 1 year old because they do not have the mask for older patients. This is a function of service and commissioning levels. As a result, ABC has on occasions been transferred to Great Ormond Street for non-invasive treatment other than HFNC. It appears that it is not practical for her to be taken directly to a hospital other than Northwick Park, partly because of the additional time involved and partly because Great Ormond Street is a referral hospital. Having reviewed the position, Northwick Park Hospital, in consultation with Dr S from Great Ormond Street, have agreed to administer CPAP through the nasal pharyngeal airway rather than through a mask, which should reduce the number of transfers required.

38. Invasive ventilation is essentially via intubation. According to the clinicians, whose evidence I accept, the establishment of invasive treatment in and of itself adds to ABC's suffering and increases the risks to ABC:

i) Pre-oxygenating a patient (a necessary part of the process) requires manually positioning the patient's airway, occasionally inserting a tube to assist, and clamping a mask to the face.
ii) The process of intubation involves placing a laryngoscope in the mouth, likely to be uncomfortable and stress inducing.
iii) Securing the tube and assessing the tube position is similarly likely to cause considerable pain.
iv) It is initiated with an anaesthetic and sedation. Sedation can cause confusion and delirium. But prolonged sedation makes weaning her off the ventilator more difficult. Thus, ABC has had only minimal sedation, which in turn causes distress.
v) Suctioning during intubation would be, according to Dr S, much more painful for ABC than suctioning during a normal day because it extends further.
vi) The need for investigations such as blood gas measurements requiring skin prick testing with a lancet.
vii) The need for repeated x Ss.
viii) Invasive ventilation is known to cause damage to the lungs of a young child as a result of the high pressure which increases the probability of further ventilation need going forward. This process is known as barotrauma.
ix) Emergency intubation of children is associated with adverse events in almost a quarter of patients, with 10% suffering serious adverse events including death.
x) Many of these processes would be stress inducing events for ABC, and would trigger severely painful dystonic episodes.

Tracheostomy

39. Notwithstanding that the long-term tracheostomy authorisation sought by the applicants is no longer opposed by any of the parties, I consider it appropriate to set out my views as to why it is appropriate to grant it. Essentially, I accept the clinical view that a long-term tracheostomy would increase ABC's burdens:

i) Such tubes can get easily blocked unless suctioned regularly. The tracheostomy tube is the main airway for breathing, whereas with her current nasopharyngeal prong, if the prong gets blocked it only partially blocks the airway.
ii) Infection is commonplace.
iii) There is a risk of blockage.
iv) Suctioning is more painful than her current suctioning of the prong, because it is deeper in the airway which is much more stimulating and painful. Adults have described the pain as being a source of moderate or severe worry, and the experience can be described as excruciating. It is required several times a day.
v) Tracheostomy requires a high degree of skilled care around the clock and has a significant impact on mobility e.g going out.
vi) Tracheostomy often provides a bridge to treatment but in ABC's case there is no prospect of recovery or beneficial treatment. It is not a destination therapy. ABC is already able to breathe at a baseline, so there is no justification for a tracheostomy which is designed for people who cannot provide enough oxygen to the lungs.
vii) A tracheostomy will not reduce the dystonic episodes or prevent the need for hospital admission when she becomes unwell with infections and aspiration difficulties.

Respiratory status

40. ABC's respiratory status is very precarious, and any slight worsening can lead to rapid deterioration. She is constantly at risk of airway obstruction and inability to breathe. Her admissions to hospital needing breathing support are because of:

i) An abnormal airway tone leading to obstruction;
ii) Secretions and food can go into her lungs rather than stomach;
iii) Her dystonia at times means she cannot move her chest wall enough to breathe.

Dystonia

41. Dystonia is a disorder characterised by involuntary muscle contractions. ABC's baseline dystonia, that is to stay her normal state, is such that her trunk is as stiff as a board. When she has dystonic episodes, she experiences some or all of the following; her chest will splint, her heart rate increases, her face becomes red, her back arches, her limbs extend, there is an occasional soft cry, or whimper, and (occasionally) tears, although there is a possibility that tears are a reflex rather than a sign of pain.

42. The clinicians know from experience of other, communicative, patients, that baseline dystonia is in and of itself a cause of suffering. Accordingly, ABC is likely, when awake, and even when apparently stable and comfortable at home, to experience what Dr M described as a very painful, and continuous, degree of suffering. When ABC experiences dystonic crises, or episodes, the level of pain is likely to be, in his word, "excruciating".

43. ABC's dystonia, in my judgment, is generally painful even when there is no actual episode in progress. Thus, even at her best at home, it is a life of very painful discomfort and suffering for ABC who will experience pain from stiff joints. The doctors all told me, and I accept, that ABC probably experiences a level of discomfort and pain, when awake, on a continuous or near continuous basis. The dystonia regularly worsens

several times a day when triggered by the muscles contracting forcefully and repeatedly during an episode of distress or agitation, such as when ABC is positioned, or her airways are suctioned, or she receives chest physiotherapy (twice a day and described to me by the physiotherapist as "very uncomfortable" for ABC), or she soils a nappy, or triggered by acid reflux; such episodes are thought to last a matter of perhaps 10 seconds or so, but can be very frequent and often in quick succession. I was shown records of the carers who assist ABC at home, which, for example, refer to 11 episodes in 10 minutes on 27 May 2021 and 30 episodes in 1 hour on 28 May 2021, identifying responses such as arching the back and stretching limbs. I do not doubt that each one must be very painful; cumulatively they must be agonising. Medication for dystonia (which relaxes rigidity) assists in mitigating the frequency of dystonic episodes, but it can worsen the chest situation by reducing the muscular drive to breathe. During such dystonic episodes, the pain and discomfort increases to the excruciating level described by Dr M. Of course, the pain felt is accentuated by ABC's inability to communicate at any level.

44. It is noted by Dr C, consistent with the parents' views, that when held by M, ABC's dystonia was visibly less, suggesting comfort and amelioration of her pain. Dr B was cautious about this, considering that stimuli such as touching have a neurological impact of modulating dystonia rather than enabling the ABC to experience comfort. However, and as he fairly acknowledged, the fact that no other person appears to have the same impact when touching her would appear to provide some foundation for me to find, as I do, that M's tender holding is soothing and reassuring in a human sense, rather than a neurological sense. But I consider that at most this presents some amelioration of pain, rather than any active, or positive, pleasurable experience.

45. I acknowledge also that the clinicians are likely to see ABC at her worst, during intensive care admissions, although they also see her for a day or two after stabilisation and before discharge. It seems clear that the situation for ABC at home is less painful than at hospital; in itself, that indicates the likely increase in suffering should invasive ventilation in hospital be required. In my judgment, the balance of evidence is that ABC (i) experiences pain from her dystonia almost all of the time when she is awake, and (ii) triggering events occur several times a day and generate more intense pain, to an excruciating level. The comfort of parental care and home surroundings helps mitigate the level of pain, but ABC is trapped in a body which causes her near constant suffering

Visual and auditory perception

46. In my judgment, it is likely that ABC is almost entirely oblivious to light and sound, not fixing her gaze or turning her head or eyes responsively. Her only response to sound is a startled one, which increases her dystonia. None of the clinicians, or staff on the wards, have observed any evidence of visual or hearing perception.

47. ABC has had at least 10 visual assessments carried out by Dr B, including Visual Evoked Potentials tested on 3 August 2021. There is no evidence that she can fix and follow with her eyes. The findings suggest that her vision is severely impaired, although there is some electrical activity. Dr B on examination could detect no response to light or movement, and he would be very surprised if she can see anything. At best, he thinks

she might be able to tell the difference between darkness and light. He says she is at the extreme end of severe neuro-disability.

48. Dr B considers that the three videoclips provided by F appear to him to be very short and random. They are not evidence of reproducible movements responding to stimulus. He shared the clips with the head of the neuro-disability team at Great Ormond Street Hospital, Dr J(2), whose view is that "it was impossible to say from these clips whether ABC was fixing or following a target. It was also not possible to tell whether she was responding to sound". His view is that (i) there would need to be much more evidence of consistent responses to stimuli and (ii) he himself has not seen anything during all his involvement with ABC, including multiple assessments, to indicate any such responsiveness.

49. A medical note dated 6 April 2021 records a playworker referring to ABC "responding more to sound". Dr B's view is that the playworker has not training in such matters and little weight can be attached to the observation; I agree.

50. I was referred to a note by Dr J, a consultant audio vestibular physician, which says:

> Assessment and Plan[MC.1T]
> Fractured leg followed up at NPH.
> CMH suspecting ANSD
> Responding more to sound
> Turned to clapping sounds without visual cues

The note was based on what s/he was told by F during a discussion. So far as anybody is aware, Dr J did not carry out an assessment. S/he was not called to give evidence. On balance I am not inclined to attach any meaningful weight to this note, and prefer to adopt the evidence of Dr B who has carried out multiple assessments and gave clear and cogent oral evidence to me.

51. It seems to me that the 3 videoclips relied upon by F are not of themselves sufficient to reach a finding that ABC is responsive to visual or auditory prompts. These are 3 short clips. F's evidence as to his belief that ABC responds to his verbal prompting 4-5 times out of 10 seemed to me to be expressive of yearning for reaction rather than evidence of ability to see and hear. The preponderance of evidence from the clinicians, ward staff and second opinion doctors is to the effect that there is no meaningful interaction with the world. In my judgment, F, entirely understandably, is basing his assessment on hope, which is not truly backed up by the evidence. There is simply no pattern of reproducible responses. More likely, in my view, is that the movement of the eyes is random and unconnected. If there is any interaction at all, it can only be on the rarest of occasions, and for the most fleeting of moments.

The ceiling of care

52. All the doctors were clear that at present the treatment, insofar as it includes invasive ventilation, goes too far. Their own belief (particularly that of Dr M) that they may be acting cruelly, and the sense of distress experienced by those on the ward who care for ABC in hospital and see her suffering, as expressed to me by the Ward Manager, was almost palpable. All the doctors consider that there should be a ceiling of care limited

to non-invasive ventilation. Invasive ventilation would, in their view, prolong ABC's life and suffering with no discernible benefit in terms of quality of life. Invasive ventilation is by itself painful. All agree that she experiences pain and discomfort, even at her best, and there is no indication of any joy in her life. There may be moments when ABC is not suffering, but she has periods of acute distress, her enjoyment of life is severely limited, and it is not in her interests to receive invasive treatment.

53. To withhold treatment in the manner sought would likely shorten life (although that is not guaranteed) but will reduce the degree of suffering experienced by ABC.

Conclusions

54. I propose to draw the threads together.

55. I readily accept and agree with the proposition that there is a presumption of life, albeit such presumption is rebuttable and can give way to other factors. I am also satisfied without reservation that ABC's life, no matter how impaired, has inherent value. She is surrounded by a loving family who are devoted to her. I do not underestimate the benefit of being cared for by parents to whom I pay the utmost tribute for their devotion and love. ABC brings joy to her parents and sister. I bear in mind also that in principle ABC would likely want to be at home, enveloped by the love of her family, although it is also likely that she would wish to avoid pain and regular hospital admissions. I also take into account the family's religious views, which merit the utmost respect. ABC herself would have been raised in Islamic faith, but at this stage of her life, and in this condition, she does not hold any concept of religion. ABC would no doubt be influenced by her parents' views, but she remains an individual in her own right.

56. I accept the evidence of the clinicians and second opinion doctors. On the rare occasions where they conflict with the evidence of the parents (and such conflict is not as to factual matters but entirely understandable interpretation of facts and events, and the weight to be attached) I prefer their assessment, based on long experience of assessing and treating catastrophically ill children. They are better able than the parents to interpret and extrapolate from the available information.

57. I conclude that ABC has little (or more likely, in my view) no meaningful interaction with the world. The evidence of clinicians and ward staff, taken as a whole, as to her lack of visual and auditory responsiveness is compelling. Any visual or auditory interaction is at a negligible level, and she is unable to communicate.

58. It is, in my judgment, of note that although M believes there are some benefits to ABC's life, in particular her responses to touch, she nevertheless considers that such benefits do not justify opposing the application. As the person who is responsible for the comfort and reassurance provided to ABC, I consider her intuitive sense of the right way forward to carry considerable weight.

59. Much of ABC's life revolves around events (including medical treatment) associated with pain and suffering. I am quite sure that M is able to soothe by touch, but these are likely to be times when pain is mitigated rather than erased, and the underlying bodily condition is one of constant pain and suffering when awake. Even the times of stability at home, notwithstanding the exemplary care provided by her parents, are likely to be

painful and distressing. Basic everyday tasks and functions cause pain. At best there might be periods of relative calm, but it is difficult to categorise such times as pleasure in themselves, particularly when accompanied by pain. The evidence of excruciating, pain during dystonic episodes is, in my judgment clear. Her inability to communicate her pain must in itself be agonising.

60. I am satisfied that ABC derives no pleasure or joy from her life or the world around her. At most, she experiences intermittent reduction in pain.

61. It is not in dispute that ABC has no realistic prospect of recovery from, or even minor improvement to, her life limiting conditions. Her prognosis is for complications of her dystonic cerebral palsy (including fractures, pressure sores, bony deformities and infections), continued need for suctioning, repeated episodes of breathing difficulties, repeated need for ventilation (non-invasive and invasive) and continued need for round the clock care. Her life expectancy is severely compromised. She is locked into a cycle of episodes of stability punctuated by episodes of extreme suffering.

62. I acknowledge and agree that non-invasive ventilation does not, by itself, increase her pain or suffering to such a degree as to justify removing that essential source of treatment. ABC appears to tolerate non-invasive treatment, which provides her with relief when struggling to breathe. Invasive ventilation, by contrast, on the clear evidence set out above would be likely to increase her pain and distress to a very significant degree with no improvement to her quality of life. True, it may prolong life (although that is not completely certain) but without any increased benefit in her experience of life. On the contrary, it would be, in my judgment, detrimental to her in that prolonging life would inevitably prolong distress, pain and suffering. Even if the number of admissions for invasive ventilation is relatively rare, because of good management with non-invasive ventilation and medication, the simple fact is that each and every treatment by invasive ventilation would be extremely painful and distressing for ABC. Such admissions requiring invasive intervention are likely to increase, particularly as her condition deteriorates, and the pain and suffering will continue in a repeated cycle

63. Counsel for F pointed rightly to the improved presentation of ABC since November 2020 and extrapolated from that a proposition that future admissions for invasive ventilation may be limited in number and duration (he suggested once or twice per year). Although I take on board the point in general terms, the medical evidence is that ABC is likely to deteriorate. To attempt to assess the number of such admissions is difficult, but on the evidence I have heard it seems likely to me that they will increase over time beyond one or two per year. In any event, I agree with M and the Guardian, who both thought that “only” one or two such admissions would not be rare, and should not be endured by ABC.

64. I do not accept the submission of F that ABC’s existing burden (in the sense of the high degree of intervention and pain, together with minimal awareness and responsiveness) is a baseline such that the issue becomes purely whether the added burden of invasive ventilation is justified when set against the existing level of intervention which has been deemed by the clinicians and the parties to be acceptable. Paradoxically, that would suggest that the greater the level of suffering, the less justification there is for authorisations limiting treatment, which seems to me to be illogical. No best interests analysis has previously been carried out by the court. It seems to me that I have to look

at the case holistically, and balance benefits and burdens in the round. That must include an assessment of the existing quality of life, its benefits and burdens, on its own merits and not as a fixed point of reference. If, however, I am wrong about this, and I should confine myself to an analysis limited to, or focussing on, the additional burdens of invasive ventilation, I would have no hesitation in reaching the same conclusion. The evidence as to those additional burdens, which I have outlined above, is compelling and it is clear to me that to subject ABC to such treatment would be unjustifiable, and not outweighed by such negligible benefit (in the widest sense) as she may derive from life.

65. The balance between benefit and pain is, sadly, clear. ABC derives negligible (and probably no) direct benefit from her life in the sense of experiencing joy or pleasure; at most she experiences some intermittent soothing. By contrast she experiences what I judge to be constant pain, even during the times of stability; that pain regularly reaches excruciating levels. Each day she experiences dystonic pain in the variety of day to day caring activities, and her own functioning. This little girl, despite everything that could possibly be done for her by her parents, and the clinical teams, is suffering, at times, in my judgment, agonisingly so. Invasive ventilation prolongs, or sustains, life, but generates considerably increased pain and suffering. It is hard to conceive of admission for invasive treatment as anything other than an utterly agonising experience for her.

66. I have been guided at all times by ABC's best interests. In the end, and with a very heavy heart, I consider this to be a clear-cut decision. I have reached the clear conclusion that the applications should be granted, and a ceiling of ventilation treatment limited to that which is non-invasive must be authorised. That is the combined view of all the clinicians and second opinion doctors, and the Guardian. M does not oppose the applications. F's opposition to the applications is wholly understandable but in my view the applications should be granted. The palliative care plan should be implemented in the event that non-invasive ventilation is insufficient to sustain her life. Such an outcome is required in the best interests of ABC. It is consistent with human rights considerations to which I have referred, being necessary and proportionate.

67. I know this will be painful and difficult for the parents, to whom I pay tribute for their fortitude, composure, and courtesy. They have done everything possible for their daughter and no doubt will continue to do so until the inevitable time comes, whether sooner or later.