Neutral Citation Number: [2023] EWHC 134 (Fam)

Case No: FD22P00753

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 27.01.2023

Before :

MRS JUSTICE MORGAN

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Between :

An NHS Foundation Trust	**Applicant**
- and –	
(1) Kwame, by his Children's Guardian Ms Kathleen Cull-Fitzpatrick	
(2) WX	
(3) UV	
	Respondents

- -

Fenella Morris KC (instructed by Clementine Robertshaw, Hempsons) for the **applicant**
Maria Stanley (instructed by CAFCASS Legal) for the **first respondent**
Victoria Butler-Cole KC (instructed by Sophie Wells, Leigh Day) for the **second respondent**
The third respondent UV appeared in person

Hearing date: 16th January 2023

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Approved Judgment

This judgment was handed down remotely at 10.30am on 27.01.2023 by circulation to the parties or their representatives by e-mail.

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MRS JUSTICE MORGAN

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.

Mrs Justice Morgan :

1. The young man who is the subject of this application, I will call, at his mother's suggestion, Kwame. Kwame had his 16th birthday last month but rather than standing on the brink of adulthood and looking to the future, his tragedy, and the tragedy for all who love him, is that he is, instead, the subject of an application for declarations made by the applicant Trust in relation to withdrawal of life sustaining treatment.

2. It would be all too easy to lose sight of who Kwame really is, because the young man who is the subject of this application has been in many ways diminished. His mother was clear that she wanted me to know about him as a 'person' not just as a 'patient'. From the statement she prepared for these proceedings, a little more emerges of Kwame, the person. His father told me that, in the picture she gave of him, Kwame's mother captured it '*perfectly*'.

3. Before May 2021 Kwame was very sporty and athletic. He was particularly good at basketball. He was on the school basketball team and was very dedicated to it. Being so tall for his age helped him with that. Kwame's appearance mattered a lot to him, and his mother described how before going out he would take ages in the shower and then moisturising and then finally in very carefully combing his afro over and over in the same spot to make sure it looked just right. His popularity with his peers is reflected in the fact that at his recent birthday his friends turned up at Kwame's bedside with cards to spend it with him.

4. He is a very much-loved member of a large and close-knit family. He has an older sibling and 2 younger ones and is a responsible boy feeling his role as the oldest boy in the family keenly. He tried to set a good example. He has always been close to his younger siblings and they in turn look up to him and respect him. He joined in the family passion for film and cinema and still more the family interest in food. He comes from a family of good cooks and had recently started to learn to cook. His bright and inquisitive mind led him to be interested in and express thoughtful analytical views about social issues, prominently amongst them Black Lives Matter. His mother says he has always been a quiet boy and a deep thinker. She says he is just like his father. At this hearing his father, with a broad smile on a day when smiles were few, said to me that she was exactly right.

5. In May 2021, Kwame was found unresponsive at his home after what it seems was an attempt to take his own life. Despite efforts made by those who found him and by emergency services he remained unresponsive. He suffered a hypoxic cardiac arrest and for at least 28 minutes had no recordable heart rate. He was intubated at the scene and taken by air ambulance to hospital. Following admission, he was transferred to the Paediatric Intensive Care Unit (PICU) where, intubated and ventilated he has been treated ever since. He has remained there for the last 20 months. I will consider later in this judgment the investigations and procedures carried out during that time. The medical staff and clinicians looking after him have done so with a dedication and kindness which I have been told his family has very much appreciated. It is however sadly the case that all of that care; all of the expertise; all of the hope that it might be otherwise, cannot alter the reality that the clinical evidence before me is that there is no hope of a recovery or even of improvement.

6. It is in these circumstances that the Trust makes its application for a declaration that it is not in his best interests for life sustaining treatment, including mechanical ventilation, to be continued and that he should be moved to a palliative care pathway.

The Parties' Positions on The Trust's Application

7. The Guardian Ms Cull-Fitzpatrick supports and agrees with the Trust's application. Kwame's Mother does not oppose the declarations sought by the Trust though she cannot bring herself positively to agree. Kwame's father does not agree. He would wish Kwame to be given some more time to recover and makes the point that no one can know now what might be possible by way of new treatments becoming available or medical developments in say a year's time. If, however, the court comes to a different view he is willing to accept the decision made.

Representation and Participation at This Hearing

8. The Trust has been represented by Ms Morris KC, the Guardian appointed to act for Kwame, by Ms Stanley. Kwame's mother has had the benefit of representation by Leading Counsel both at this hearing and at the hearing listed in December 2022, today by Ms Butler-Cole KC. Kwame's father had initially indicated that he did not wish to engage further in any discussion or have any involvement in the application. When the application came before me on 1st December 2022 attempts had been made to serve him with notice of the application at an address but there was lack of certainty that the material had reached him or that I could be confident that he knew of it. Given the seriousness of the issues to be considered, I directed that further efforts should be made to engage with Kwame's father before considering whether in these circumstances I should deem him to have notice. I have been enormously grateful to the Guardian for her proactive and sensitive approach in making contact with the Father.

9. The Guardian successfully made contact with the Father by telephone and WhatsApp speaking to him on 15th December 2022, 22nd December 2022 and 4th January 2023 (he having indicated that he felt more comfortable speaking by phone than in person). During these conversations he confirmed that he had received documents that had been left for him at the address where service had been attempted and that he had read all the documents served up to and including the time of his second conversation with the Guardian on 22nd December 2022. There is a considerable amount of detail set out in the position statement of the Guardian as to the communication between the Guardian and the father which it is not necessary for me to rehearse here, but for which efforts I express my thanks to Ms Cull-Fitzpatrick. It is sufficient to say that the Guardian's efforts resulted in the Father providing an email address which was subsequently used to serve updating statements on 4th January from the Trust and the Guardian's report on 5th January 2023. Whilst there was in the run up to this hearing some doubt as to whether Kwame's father had accessed all of the more recent documents sent to him by secure means he told the Guardian that he would attend this hearing and he did so. He confirmed to me that he had received all of the documents and that he had also been provided with a hard copy of them at court.

10. It was known that the Father intended to represent himself at the hearing and he came accompanied by a friend for support. He told me sadly and frankly that he did not want to be here. There had been a suggestion within the papers that Kwame's father did not wish in any event to instruct a solicitor or to ask for time to find representation and I asked him about this. He agreed that this was so but added also that the reality was that even if he wanted to the cost would be prohibitive. As it was, he expressed his position with a quiet dignity and was able to convey to me those questions he would wish to ask of the medical witnesses. Since it was his preference that I asked the questions for him rather than he asked them himself I did so. I observe in passing however that it is dispiriting that the vagaries of the funding provisions are such that this quiet dignified father facing the worst experience imaginable should not have been able to be represented had he wanted it.

The Legal Framework

11. There is no dispute as between the parties as to the legal framework which governs the decision to be made for Kwame. As Mr Justice Poole observed in *Guys and St Thomas' Children's NHS Foundation Trust and Pippa Knight [2021]EWHC 25* the law applicable to decisions of the kind this court is required to make in respect of a child, has been set out in numerous cases. I do not in this judgment intend to travel through all of them.

12. The key principles articulated by the Court of Appeal in *Portsmouth Hospitals NHS Trust v Wyatt and Anor [2005] EWCA Civ 1181*, and by Holman J in *An NHS Trust v MB [2006] EWHC 507*, remain apposite today. They are that i) The judge must decide what is in the best interests of the child. ii) In making that decision the welfare of the child is the paramount consideration. iii) The judge must look at the question from the assumed point of view of the child. iv) There is a strong presumption in favour of a course of action that will be likely to preserve life, but that presumption is not irrebuttable. v) The term "*best interests*" encompasses medical, emotional and all other welfare issues. vi) The court must consider the views of the doctors and parents. vii) Each case will turn on its own facts. viii) The court must conduct a balancing exercise in which all relevant factors are weighed. This is not a mathematical exercise, but it is an objective one. It is important that Kwame's family understand that *each case will turn on its own facts* means that when a decision is to be made about Kwame it is a decision about him; what had happened to him; his particular circumstances and that just because other families have found themselves in similar terrible situations does not mean that there is a 'one size fits all' answer.

13. More recently, in *Re A (A Child) [2016] EWCA Civ 759*, the Court of Appeal made the point that [31]:

> "*Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005. In Aintree University Hospital NHS Foundation Trust v James [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 22:-*

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

And from paragraph 39:-

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

14. In the *Pippa Knight* case Poole J acknowledged, as do I, how harshly must the words of Holman J strike the ear of parents such as these when in *An NHS Trust v MB*, Holman J said this of parental views, "*Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.*" They are words however that serve to remind with emphasis, a Court making this sort of decision that the child's welfare is paramount. I found echoes of this aspect in the Mother's statement of evidence in this case when she set out how she had tried in her own thinking about the decision to be made for Kwame to disentangle what she would want for herself from what would be the best thing for him.

15. When considering the decision from Kwame's point of view, the evidence as to what his attitude to treatment is or would be likely to be must be considered and given appropriate weight having regard to his age and understanding (*Raqeeb v Barts NHS Foundation Trust [2019] EWHC 2531 (Admin) at [116v]*). Kwame's father has in this respect been able to speak in discussions of Kwame's response to seeing when he was a much younger child an older relative incapacitated and bedbound following a stroke which had seemed to him then to be a prospect which Kwame had thought of with some equanimity as contentedly lying in bed living a life. So it is that the Father thinks perhaps Kwame might take the same view of his own position now. I have to factor into the fact that Kwame's age and understanding when he expressed those views was very different. It is hard to see how the older Kwame, the sportsman, the sociable young man who had become so particular about his appearance would be likely to be so content. In his conversations with the Guardian during her helpful and

sensitively conducted investigations, the Father recognised this. I have reminded myself of the review of the applicable law by Hayden J in *Re H [2022] EWFC 14* and especially those matters he sets out from para [37] including *what would the child's attitude to his circumstances be, including what was and would be important to him.*

16. I note also that as Ms Stanley reminds me on behalf of the Guardian religion and culture are also important factors to be taken into account when assessing a child's best interests see Baker LJ in *Fixsler v Manchester NHS Foundation Trust [2021] EWCA Civ 1018* at [81]

"*The family's religion and culture are fundamental aspects of this child's background. The fact that she has been born into a devout religious family in which children are brought up to follow the tenets of their faith is plainly a highly relevant characteristic of hers. Under s.1(3)(d), the court is required to have regard to the fact that Alta is from a devout Hasidic family which has very clear beliefs and practices by which they lead their lives and that, if she had sufficient understanding, she too would very probably choose to follow the tenets of the family religion. I agree with Mr Simblet that this is a central part of her identity – of "who she is". It is unquestionably an important factor to be taken into consideration. But it does not carry pre-eminent weight. It must be balanced against all the other relevant factors."*

Kwame is a member of a religious family. He, his siblings and his parents have a strong Protestant Faith. His Mother set out in her statement that she and her family have been sustained by that Faith and by prayer throughout the time Kwame has been in hospital but from neither of his parents do I detect a sense that because of their religious faith I should be swayed one way or the other in terms of the decision I should take.

17. I hold in my mind that there is a strong presumption in favour of taking all steps to preserve life because the human instinct must be presumed to be strong in the patient. However, this presumption is not irrebuttable and 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. (*Airedale NHS Trust v Bland [1993] ACR 789 at 825; R (Burke) v The General Medical Council [2005] EWCA 1003*).

18. As an element of the best interests evaluation the concept of human dignity also falls to be considered. I have had regard in this respect to the way in which Hayden J at [63]: in *North West London Commissioning Group v GU [2021] EWCOP 59* set out the following analysis "*i. human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition; ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being; iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights; iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;"*

Professional Guidance

19. This case is one in which those charged with making decisions medically for Kwame have had regard to the *RCPCH Guidance*. The Royal College of Paediatrics and Child Healthcare published the document, "Withholding and Withdrawing Life Saving Treatment in Children" in 1997. In 2015 revised guidance was published under the title, "Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice." It has been considered by the President of the Family Division in *Re Jake (A Child) [2015] EWHC 2442 (Fam),* MacDonald J in *Raqeeb* and Poole J in *Pippa*. I hold it in my mind when considering Kwame's best interests.

It is prefaced as follows:

"We emphasise two important points so as to avoid confusion:

1. This document sets out circumstances under which withholding or withdrawing life- sustaining treatment might be ethically permissible—NOT circumstances under which such treatment *must* certainly be withheld or withdrawn.

2. The document describes situations in which individual children should be spared inappropriate invasive procedures— NOT *types* of children to whom appropriate procedures should be denied."

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

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.

III:- Informed competent refusal of treatment.

Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST.

Kwame's History Following Admission to PICU

20. Throughout Kwame's prolonged stay in PICU there has been no sign of improvement in any aspect of his condition. What follows is not intended as an exhaustive history but serves as an outline of the evidence before me of the investigations and procedures undertaken without positive effect or improvement.

21. A brain MRI scan soon after admission on 7th May 2021 showed moderate-severe hypoxic brain injury involving several brain areas. Kwame continued on neuroprotective measures including paralysis and was commenced on an antiepileptic medication Levetiracetam. An echocardiogram on the 8th May showed better function of the heart and medications to support this were reduced.

22. On 10th May 2021 it was noted he had twitching of his legs when his paralysis was weaned. He had an EEG which was not specific for seizure activity despite episodes of leg twitching happening during the procedure. The leg movements were thus felt to be due to contractions of the muscles (myoclonic jerks) rather than seizures. He was continued on sedation.

23. A further brain MRI on 13th May demonstrated an evolution of the findings from 7th May 2021. The extent of the acute hypoxic brain injury was more obvious with signs of bleed in the basal ganglia. He was started on Piracetam for the repeated muscle jerks but continued to experience them. A repeat EEG on the 18th of May demonstrated epileptic myoclonus. The anti-epileptic medications were continued. He remained ventilated. On 18th May he developed a chest infection (thought likely due to the ventilator) and was treated with antibiotics. This was the first of a series of infections from which he has suffered during his stay and which are an unavoidable consequence of his situation however skilled and assiduous the care given to him. As a result he has required repeated courses of antibiotic medication over time.

24. On 26th May the first attempt was made to take Kwame off the ventilator. He was unable to keep his airway open by himself. Within ten minutes of extubation he was put back onto mechanical ventilation. His, by now very poor, upper airway tone, presented difficulties in maintaining the upper airway and a decision was made to re-intubate him and place him back on mechanical ventilation.

25. A second attempt to take him off the ventilator on 23rd June 2021 had a similar outcome. He was again returned onto mechanical ventilation within 10 minutes of extubation. Before the attempt was made there had been discussions with his parents about whether this should be what is known as a one-way extubation, i.e. an extubation with the decision to not reintubate him even if he is unable to breathe independently and provision of comfort care only. Kwame's parents were not agreeable to this option and wanted Kwame to be reintubated and placed on mechanical ventilation should he need it.

26. The continuing repeated myoclonic jerks meant that Kwame repeatedly bit his tongue and so a bite block was placed under sedation on the 30th of June 2021. A further EEG on 5th July 2021 showed no definitive epileptic activity. The findings were suggestive of severe cerebral dysfunction in keeping with hypoxic ischaemic encephalopathy. A repeat MRI on 6th July 2021 demonstrated findings in keeping with global hypoxic ischaemic injury.

27. On 7th July 2021 there was an incident when Kwame's ventilation tube became dislodged following physiotherapy. There was immediately obvious significant difficulty in breathing without it and his tube was replaced straight away. Later in July Kwame was commenced on Omeprazole to prevent damage to his stomach lining after blood had been noted coming from his feeding tube. On 20th July he required treatment with antibiotics for a urinary infection. Towards the end of July, Kwame developed a high temperature and excess secretions. He had bloods taken and commenced a further course of antibiotics - lasting 15 days - and underwent an ultrasound of his abdomen for what was a suspected ventilator-acquired infection.

28. On 13th August he was noted to have a pressure sore on his right ear requiring input from tissue viability nurses. He required a mouthguard since his teeth had become loose because of his prolonged time on the ventilator and the repeated endotracheal tube changes. These changes to the integrity of his body have increased over time. By the beginning of September 2021 it was necessary to change the endotracheal tube from the mouth to the nose because of pressure sores and loose teeth in his mouth.

29. In early September he had a further course of treatment with antibiotics for what was thought to be another ventilator-acquired infection. After less than a week another infection required another 7-day course. A further course of 5 days was required for another infection at the beginning of October.

30. Although myoclonic jerks continued throughout September, when on 1st October Kwame was assessed by Occupational Therapy, Physiotherapy and Adult Trauma Coordinator and Physiotherapist there was no response to visual, auditory or tactile stimulation and the increase in myoclonic jerks on handling were thought to be reflexive rather than deliberate.

31. In the light of Kwame's condition, on 7th October 2021 those treating him sought an external second opinion from Dr EE, Consultant Neurologist at Hospital A. The Paediatric Intensive Care team had a meeting with the family on the 12th October to discuss the results of the second opinion. Kwame's parents did not agree to discontinue intensive care support.

32. It was agreed that there would be a further attempt to extubate Kwame. His parents did not agree it should be a one-way extubation. He was extubated on the 11th November but required reintubation approximately 5 hours later. Following this he developed another bacterial ventilator-associated chest infection treated with a course of antibiotics. By 23rd November 2021 Kwame needed help with a cough assist to help manage the secretions on his chest.

33. On 9th December 2021 the Clinical ethics committee meeting at the applicant Trust discussed Kwame's case and there was consensus that it was not in Kwame's best interest to continue intensive care treatment.

34. A multi professional meeting on 24th February 2022, which included the adult neuro physiotherapy professionals, unanimously agreed that Kwame had no rehabilitation potential. The risk to Kwame regarding endotracheal tube placement and general discomfort outweighed any potential gains which may be gained by further rehabilitation therapy.

35. By 28th February 2022, it was noted that it was becoming more difficult to place the endotracheal tube due to swelling and lack of tone of the soft tissues. It was placed with difficulty and required a glidescope, a video laryngoscope (a thin tube with a light, lens

    and a video camera used to examine a patient's larynx) used for patients in whom intubation is more challenging.

36. By 6th April 2022, the endotracheal tube was changed back to the mouth because of pressure sores in the nostrils. Again, a glidescope was needed as well and precautions including the availability of an anaesthetist. Over time, there has developed a dual problem with the tubes in that replacement has become more difficult as Kwame 's larynx deteriorates, and they become more easily displaced because of the excess secretions.

37. On 8th April 2022 Kwame started having continuous myoclonic jerks and was clamping his jaws on the ETT tube impeding ventilation. A bite block and a muscle relaxant were used to prevent Kwame biting down on airway tubes.

38. On 12th April 2022 Kwame was reviewed by Dr CC, Consultant neurologist who concluded that Kwame remained in the same neurological state as his previous review in October 2021. Dr CC recorded that, *"[*Kwame*] does not exhibit any voluntary actions or movement but only responds to pain (e.g. deep tracheal suction) in a reflex manner with limb extension. He has no awareness of his surroundings. He continues with spontaneous intermittent jerks/tremors which we know from before are of a subcortical nature*".

39. In order to gather further information for decision-making about Kwame's care, repeat MRI imaging and EEG were arranged. The report on the EEG of 14th April 2022 showed no significant EEG activity changes are noted with external stimulation and diffuse fast rhythms are a non-specific finding. In the context of hypoxic brain injury, the EEG was reported as suggestive of diffuse encephalopathy of severe

degree. Those findings were similar to the previous EEG carried out 7 months earlier in September 2021.

40. On 25th May 2022 findings in a report on the "auditory evoked potential" i.e. the time it takes nerves in the auditory system to respond to sound and electrical stimulation were such that it was not possible to make any conclusions about the auditory pathways beyond the cochlea. There are no indications that Kwame hears or otherwise responds to auditory stimuli.

41. The intensivists treating him noticed that Kwame's airway support was becoming more challenging because of his reduced upper airway tone. He has needed support for his breathing on continuous positive airway pressure overnight and a BiPAP machine to help push air into his lungs during the day.

42. On 21st April 2022 Kwame was noted to have a pressure sore on the back of the head. By the next day he had a hospital-acquired ventilator-associated pneumonia and was commenced on IV Meropenem. A further infection was signalled when on 28th May he had high grade fever consistently above 39 degrees Celsius. He was started on IV Ciprofloxacin. On 7th June 2022 a further problem was discovered when a hypopigmented area on Kwame's shoulder turned out to be a fungal infection needing topical antifungal treatment.

Kwame's Present Condition

43. Kwame remains on the PICU with 1:1 nursing care. He is observed constantly. He is permanently ventilated. His regular medications include Baclofen, Clonazepam and Clonidine for the dystonia, Levetiracetam, Sodium valproate and Piracetam for seizures and myoclonus. He also has Glycopyrronium and Hyoscine patch for secretion management and laxatives for bowel management.

44. From Dr AA I accept the following unchallenged summary of Kwame's present condition

i) He is profoundly neurologically injured. His cognitive impairment is severe and irreversible. He has shown no signs of recovery in the 20 months since injury.

ii) His brain injury taken together with his inability to maintain his airway means he does not have, and on the medical evidence will never regain, any functional speech.

iii) He does not respond to any command, noise or sight.

iv) He does not demonstrate any sign of awareness of his surroundings and sadly, in light of the investigations described above and his lack of progress to date, his treating clinicians believe there is very little chance of him regaining any awareness. His condition shows no sign of improvement.

v) He has no deliberate or purposeful limb movement in response to painful stimuli, and only a weak cough reflex and gag response to direct pharyngeal stimulation. He can have periods of not breathing when he is put on the spontaneous breathing mode on the ventilator when breaths are not triggered for him by the machine. Previous

attempts at extubation have demonstrated that he lacks upper airway tone and consequently, he cannot maintain his upper airway.

Issues For The Court To Determine

45. The sole issue for me to determine at this hearing is whether it is in Kwame's best interests to continue to receive life-sustaining treatment. Ms Butler-Cole has invited me to consider giving some guidance as to how similar applications should be commenced and proceed. I understand why she makes the invitation, but I decline to accept it in this case. It may also be necessary to consider certain aspects of the reporting (and any continuing restriction of the reporting) of Kwame's circumstances but any such consideration will be more appropriate elsewhere than in this judgment where the central focus is properly on Kwame.

The Views of Kwame's Family

46. Kwame's mother has put into words in a statement filed for these proceedings not only a powerful account of who her son is and what he means to her and to his family, but an equally powerful account of how she has struggled with what she thinks would be best for her child. Kwame has been in the PICU for a long time now - more than 18 months. Through all that time his mother has visited him every week, on average twice a week sometimes only once if her other family obligations are pressing, often more if she can manage it. She has reached a position where though she does not feel the decision is one for her – and she is right about that it is for me – she does not oppose the application. She accepts the unified view of the doctors looking after him and those who have given second opinions that there is no prospect of improvement or recovery.

47. She explained that it took her a while to reach that point and one of the things that has made it so hard for her to do so is that in some ways Kwame looks well. Most of the time he looks comfortable, calm and relaxed. He is warm when she touches him. He seems to have facial expressions - sometimes tired, sometimes relaxed. He yawns, stretches, opens and closes his eyes just like any other teenage boy might. It has taken her a while to trust what the doctors tell her, that these are reflex and involuntary actions, but she does trust them. Since he has been so long in hospital he has grown and his body matured. That again is hard to square with there being no room for hope of improvement but square it she has. With conspicuous grace she says in her statement, and again through counsel, that she realises that the reason he looks so well is because the doctors and nurses have looked after him so well and she thanks them. Ultimately the point she has reached is that since Kwame first went into hospital, she has been adamant that she didn't want him to suffer. She feels now that were she to oppose the application to extubate him it would be something she would be doing more for her comfort and not for him. In some ways she has come to speak for Kwame's wider family. She has talked to his younger siblings who are understandably too young even perhaps to know what to think, still less form a clear view but his older sister has talked to her mother a lot. His sister has said she doesn't think her brother would want to live as he is now.

48. Kwame's father told me that he found the pressure of being at the hospital too much, especially once his own father died during the time that Kwame was in hospital and so although he went in to see Kwame in the earlier part of his admission there came a time when it was too much. From his discussions with the Guardian, I know that over Christmas he visited the hospital several times but could not bring himself to go in to see his son. That vignette tells me more than many words might about the pain of his situation. What he said to me in court was that he did not want anyone to think it was that he couldn't be bothered. He hadn't wanted to continue discussions at the hospital about what should happen because it felt to him like a pressure to agree that no more could be done. His position now is that he wants Kwame to stay as he is, to be given more time.

49. Although he has heard and read what the Doctors say about the prospect that Kwame might deteriorate further – his airway becoming less robust and less able to withstand the mechanics of ventilation - he says I must also consider the other side of that coin which is that he might not. Although the medical evidence is that he will be at risk of infections which might ultimately overwhelm him as they become resistant to treatment, weighed against that is that he might not. He might, says the Father just go on as he has been or at least not get very much worse. It can't be taken for granted that he will deteriorate. The reason that matters from the Father's perspective is twofold: first that contrary to the medical opinion, he might improve if given more time and second that there might be some treatment that isn't available now but will be if he can be kept alive for it because things change. If I were to grant the Trust's application, Kwame's father did not disagree at all with what his mother said should happen about the timing and place of any extubation. He didn't want to say anything different or to add to what she had said, and he didn't want to be involved in any discussions with professionals about it.

The Views Of the Medical Professionals on Kwame's Best Interests

50. In some cases where an application of this sort is made there are differences of view or a nuanced distinction between those from whom comes the medical evidence before the court. This is not such a case. Here no one from Kwame's treating team or offering a second opinion suggests either that there is a hope of recovery or that there is another option which should be taken. Nor in this case is there any other or different course of action or treatment contended for by any of the parties save and except that Kwame's father wants to wait and to give more time.

51. I have read carefully all of the evidence contained within the trial bundle. Especially relevant for me at this hearing has been the written evidence of Dr AA, consultant paediatric intensive care physician, Dr BB, consultant adult and paediatric neuroradiologist, and Dr CC, consultant paediatric neurologist, all of whom have been involved in Kwame's care as members of his treating team. Each has set out in their detailed reports why they have arrived at the position where from the point of view of their respective disciplines they support the application. Neither the Mother nor the Guardian challenge the views set out or the conclusions reached.

52. There are concurring second opinions from Dr EE (Consultant Paediatric Neurologist) at Hospital A; Dr FF (Consultant Paediatric Neurologist) at Hospital B and Dr GG

(Consultant Paediatric Intensivist) Hospital C. All of those providing second opinions agree that it would be in Kwame's best interests to withdraw life sustaining therapy and to facilitate extubation and separation from mechanical respiratory support.

53. Dr AA supplemented her written evidence by oral evidence at this hearing. In response to questions which Kwame's Father raised she explained that the team treating Kwame had seen no improvement during the more than 18 months that they had been caring for him. It is a long time to have a patient in intensive care. In intensive care she said they would give time for recovery from the primary injury and so see signs of a beginning of a recovery after say six months but here there was no sign of anything. She did not agree with Kwame's father that giving more time for recovery would make any difference because it would be impossible to grow new neurons. The damage to his brain was extensive and permanent.

54. Kwame's father wanted to know if there were any treatments or options which had not been tried but which might help Kwame. Dr AA said that there were not. Kwame's team had done everything they could think of but there was nothing else. When Kwame's father asked if she meant nothing else available at her hospital or nothing else available in the country, she explained that she meant nothing else available in the world. The Father had said to the Guardian that he thought the Trust's application was motivated by the wish to avoid the expense of treating Kwame and that were Kwame the son of a wealthy man he would go on having treatment in intensive care. The Doctor responded that the cost of treatment had never been a factor and was not part of the team's thinking. The only reasoning is that the team did not think it was right to continue treatment to no effect and which could inflict suffering. She reiterated that she was worried about the risk of an unplanned death, of Kwame being overwhelmed by infection resistant to drugs and developing septicaemia. She pointed out that he has already had to have so many courses of antibiotic treatments for the infections to date.

55. She agreed that the fact that Kwame has continued to grow, to gain height and a little weight even, might seem a strange thing but said that it was something that came from the fact that he is given nutrition and what she described as exceptional care by the nurses. I note in passing that Dr FF who had met and examined Kwame for the purpose of providing a second opinion in August 2022 made unprompted a similar observation about the quality of his care. Dr AA's view remained unchanged at the conclusion of her evidence as to both his prognosis and the best outcome for him.

56. From the detailed evidence of his bleak prognosis the following salient points may be taken

i) Kwame will never breathe for himself. Should his care continue in the long or medium term, he will require mechanical ventilation via tracheostomy throughout the rest of his life. His ventilation will need to be supported by regular and very frequent chest physiotherapy and secretion clearance. He will need a gastrostomy for feeding for the remainder of his life. He will never recover any ability to swallow and will therefore never be able to be fed by mouth.

ii) He will remain totally immobile and is therefore at risk of suffering from the complications of immobility, including stiffness and joint contracture, pressure

sores, osteopenia. Stiffness and joint contracture will require regular intense physiotherapy with or without medication. Over time he will have problems with body positioning, and it may be painful. He may require surgery involving his tendons, joints and bones to manage his contractures.

iii) Kwame's condition is so severe that he will require an extremely high level of nursing care. He would either need to remain in hospital or alternatively he may be able to reside at a neuro-rehabilitation centre. Given his complex needs and the equipment required to manage his care, along with the likelihood of emergency care being required, it is unlikely that Kwame will ever be able to return home.

iv) Kwame demonstrates some movements which are interpreted as distress during certain procedures performed in his throat area (such as suctioning) but it is difficult if not impossible to assess his capacity to experience pain because of the lack of response to stimuli on testing.

Kwame's Own Ascertainable Wishes Feelings Beliefs and Values

57. I have said already how helpful I found it to hear from Kwame's mother the pen picture of him with which his father agrees. It may be that his sister is right to say that he would not want to go on living in the way he is now, knowing as I do what a lively and vibrant person he was previously, but I do not think I can automatically assume that is so. He is on the evidence no longer capable of forming conscious wishes or having thoughts about continued treatment. I note from Dr AA's evidence that he demonstrates spontaneous eye opening and blinking with some lateral eye movements but makes no response when spoken to. His pupils are equal and reactive to light but there is no significant other reaction to the light. There is no evidence that he is able to fix or follow an object or person visually. Tellingly it seems to me given how close he has been to his family and how assiduously they have continued to visit, staff have not observed him to be any different when surrounded by his family. It is both safer and more accurate to say that I am not able to ascertain what his wishes are or might have been.

58. What I know more of are his values and beliefs which centred on his family and his friends. It follows that I without hesitation conclude that whilst he retained a capacity for awareness he knew himself to be as his mother describes it a much-loved member of a large and close-knit family. I also however regard it as permissible when I consider the helpful way in which Hayden J in *Re H [2022] EWFC 14* expressed the view that it was important to think about what might be a child's attitude to his circumstances, to think that Kwame who was so fastidious that he would comb his hair over and over so it was just right is very far removed from the young man whose head is now shaved to help with the pressure sores on his head which the evidence tells me will be a continuing issue. The gradual degrading of his body is a distressing aspect of his situation to all those who are witnessing it. When I think about what was and would be important to him, I think it would distress him too. Whilst some might regard that as a superficial matter it seems to me that it ties in with those aspects of dignity which also fall to be considered.

The Views Of the Guardian

59. Ms Cull-Fitzpatrick had prepared a thoughtful and careful report in the preparation of which she had spent time with Kwame and spoken to all of those caring for him as well as with his family. It is largely thanks to her efforts that I have heard so clearly the views of Kwame's father which have been brought into the analysis. At Ms Stanley's request the Guardian was called to give evidence. There was the opportunity accordingly for anyone who wanted to cross examine her or ask her any questions at all to do so. No one did. The conclusion she had reached in her written evidence remained unaltered as well as unchallenged:

It is with great regret that having met with Kwame, considered his medical needs and Kwame welfare in the widest sense of his social and psychological needs, in addition to his medical needs both now and in the future, I consider that it is in his welfare best interests for his life sustaining treatment to [be] withdrawn. I would recommend that the Trust support [WX] and [UV] to prepare a palliative care plan and make arrangements for Kwame's death which ensures that his siblings are supported. I hope that the family continue to find comfort in their faith and in each other.

Should the court determine that the declaration sought by the Trust is in Kwame's best interest, a palliative care plan should be agreed which details how withdrawing Kwame's care would be implemented. [WX] and the Trust have agreed that this would take place in Kwame's current hospital bed, so the timing and availability of the hospital Chaplin will need to be considered. It is important that Kwame dies peacefully and surrounded by his family.

Kwame's best interests

60. I accept the overwhelming and unified medical views of those who have cared for so long for Kwame and of those who have provided second opinions as to his situation. It drives me to the inevitable conclusion that he has no prospect of improvement with treatment or, as his father urged me to consider, with more time. As to the question of more time I cannot on all that I have heard and read regard it as a neutral step to leave Kwame as he is, against the prospect that as his father hopes medical science may evolve and next year there may be something that can be done for him. The way in which his physical condition has started to degrade notwithstanding the excellent nursing care is clear from the review elsewhere in this judgment of his time in PICU since admission. Despite that care his body is degrading; infections come more often and I accept are likely to be increasingly resistant to antibiotic treatment. His skin is starting to be affected by sores and infection; the deterioration in his larynx makes the mechanics of providing ventilation more difficult and more dangerous – in circumstances where one cannot be sure whether he feels discomfort; or pain; or nothing. I accept the evidence of Dr AA that there is a risk of an unplanned death in which any attempted resuscitation would be both distressing to him and unlikely to be successful.

61. On the evidence, it seems that he cannot breathe, communicate, hear (probably) or see (so far as response to stimulus can tell) those around him. He appears to have no awareness of his environment, no purposive movement, no response to tactile stimulation. Of course, there are aspects wider than the purely medical. That those

who love him would no doubt continue to be at his side is something from which he cannot derive any subjective benefit by being kept alive.

62. It so happens that in this case one cannot be completely sure that he feels no pain – to the extent that where clinicians think there is a possibility that he might, he is medicated accordingly – but I would reach the same conclusion were the evidence to be that he feels no pain.

Declarations

63. For the reasons given I am satisfied that it is not in Kwame's best interests for mechanical ventilation to continue and that it is contrary to his best interests for it to be continued.

64. On extubation it is likely that Kwame will survive for a very short time only perhaps hours or even minutes. On withdrawal there should be defined limits on the treatment provided to Kwame, as I anticipate will have been largely agreed by discussion between the parties in relation to the care plan of palliative care, to allow him to die. Those limits will be set out in the order which follows this judgment.

65. The place where Kwame is to die when ventilation is withdrawn is unlikely ultimately to be contentious. I was told that there would be discussion about that. Kwame's father did not want to be involved in that discussion and would agree with whatever his mother thought best. I am confident that whether it takes place in the PICU where Kwame has been since May 2021 or elsewhere in a hospice setting the extubation can be arranged to be undertaken by skilled and specialist staff who will than provide such palliative care as may be necessary in the short time that Kwame will remain alive.

66. The Declarations I make are that it is lawful and in Kwame's interests that:

i) It is not in Kwame's best interests to continue to receive mechanical ventilation

ii) It is in Kwame's best interests that there be defined limits on the treatment provided to him after that withdrawal of mechanical ventilation with the effect that he will be allowed to die and it is not in his interests to receive further life sustaining treatment.