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Case No: FD25P00374

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
SITTING AT THE MANCHESTER CIVIL JUSTICE CENTRE

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 02/04/2026

Before :

THE HONOURABLE MR JUSTICE HAYDEN

- -

Between :

Manchester University NHS Foundation Trust

Applicant

- and -

(1) M

(2) F

(3) G
(A Minor by her Children's Guardian)

Respondents

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Sam Karim KC and Richard Borrett (instructed by **Weightmans LLP**) for the **Applicant**

Chris Barnes KC, Bibi Badejo and Ralph Marnham (instructed by **Stephensons Solicitors LLP**) for the **First and Second Respondents**

Fiona Holloran (instructed by **Cafcass Legal**) for the **Third Respondent**

Hearing dates: 25th to 27th and 30th March 2026

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Approved Judgment

This judgment was handed down at 2pm on 2nd April 2026 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

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THE HONOURABLE MR JUSTICE HAYDEN

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 and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Hayden :

1. This application concerns G, who is a seven-and-a-half-year-old girl. G's history is a profoundly disturbing one. In circumstances which are unprecedented to any of the professionals in the case and to the Court, she has spent approximately six years of her short life in a Paediatric Intensive Care Unit (PICU). Unsurprisingly, there is a consensus amongst all involved that this is not, nor has it been for some time, the right place for her to be. Further, the evidence reveals that there has been wide agreement amongst the treating clinicians and the family that these arrangements have been contrary to her best interests since, at least, January 2021. For now, I simply state this as a fact because it identifies the backdrop against which the decisions in focus here require to be taken. Later in the judgment, I will look at the explanations that I have heard which seek to explain this unconscionable delay, as I find it to be.

2. G has sustained extremely severe brain damage, the aetiology of which remains undetermined. Dr. Ross Russell, Honorary Consultant Paediatrician at the Addenbrookes Hospital, instructed as an independent expert in these proceedings, has surveyed the major themes triggering G's repeated acute deteriorations and many admissions to intensive care, where, as foreshadowed, she has remained permanently since March 2021. He discovered that whilst it is certainly true that on some occasions an acute viral or bacterial infection has been identified as a cause and that on many occasions, she has received intravenous antibiotics, there have also been other occasions where no infection has been found. This leads him to the conclusion that the underlying problem is central hypoventilation (a rare disorder where the brain fails to regulate breathing adequately). The importance of this, which is not challenged, is that such an abnormality of brain stem function is said to be found *"only or at least usually"*

in children with the most severe form of brain injury. It is not amenable to treatment and G will not recover. It is important that I state that across the whole range of extremely experienced consultants in the case, this fact is agreed. Though I am sure the parents understand this, they do not accept it. They believe G to be tenacious in her hold on life. They attribute to her a physical and psychological resilience which they believe will ultimately enable her to triumph above this grim prognosis. They have both faith and hope, but they do not have medical support on which to support either.

3. None of what is set out means that G is unable to breathe. On the contrary, she has demonstrated her capacity to breathe independently on several occasions when she has been disconnected from the ventilator. Sometimes, she has been able to breathe for significant periods of time. However, Dr. Ross Russell emphasises that key to understanding G's respiratory challenges is to recognise its unpredictability. The control is precarious and breathing may become perturbed or fail unpredictably at any time. This may be associated with infection or minor illness, but it may not be. It also occurs entirely spontaneously. This presents the primary challenge to the management of her condition.

4. One further important feature illuminating the severity and extent of her condition is the sustained evidence of brain stem dysfunction manifested by G's variability, both in respect of her breathing rate and her heart rate. This is thought likely to be a form of dysautonomia, an instability of the autonomic nervous system. Thus, G's control of her breathing is liable to fail, entirely unpredictably, were she not to be ventilated. I have endeavoured here, at the beginning of this judgment, to identify the key facets of G's condition in plain terms because an understanding of this is essential when evaluating

any of the limited options for G's future. I have been told, on a number of occasions, that the parents have struggled to understand aspects of the medical evidence. This is said to have been, in part, because their primary language is French (Congolese) and also because the troubled history of this case has silted the channels of communication between the doctors and the family. It is likely that there is some force in both of these. This extraordinarily protracted period in PICU has taken its strain on all involved. The unit can frequently be noisy, as all intensive care units are. It is also very warm, and the challenges G faces take their inevitable toll on nurses, treating clinicians, and, most importantly, on family members. G's mother, M, has barely missed visiting G on any of the 1,849 days of her most recent admission. She has been assiduous in monitoring her daughter's care and vigilant to promote her treatment. I am also clear that part of the difficulty in confronting the full force of the medical evidence is that the parents simply cannot bring themselves to. They hold strong religious convictions in relation to the sanctity of life which do not provide them with the emotional scaffolding from which to address the complexities and nuances of some aspects of the medical evidence.

The Legal Framework

5. It is relatively easy to state the applicable framework of the law in this sphere. Nonetheless, the interplay of the various medical, legal and ethical issues can be complex. Balancing the weight to be afforded to the sanctity of life against the burdens of treatment to a patient involves an assessment of considerations lying in different planes; they are incapable of being measured by a common metric. The lodestar remains the Supreme Court's decision in *Aintree University Hospitals Foundation Trust v James* [2013] UKSC 67; [2013] 3 WLR 1299, which emphasises the importance of framing the question facing the Court in the correct manner, i.e. whether the

contemplated treatment is and continues to be in the best interests of the patient. It is never a question of whether treatment should be withheld. This is not mere semantics; it is the structure by which the focus is fixed upon the patient's continuing best interests. Further, when considering whether treatment may be futile, this requires considering whether it would be ineffective or of no benefit to the patient. Importantly, where a patient is suffering from an incurable illness, disease, or disability, as G is, it is unhelpful to *"talk of recovering a good state of health. The patient's life may still be very well worth living"* (per Baroness Hale, paragraph 44).

6. In both his written and oral evidence, Professor Playfor, Consultant in Paediatric Intensive Care Medicine, has asserted, with striking candour, that there is *"no dignity in G's position"*. Moreover, in response to questions, he considered this as having been the situation for a number of years. Even to those familiar with these difficult and ethically challenging cases, those are arresting and chilling observations. Professor Playfor adds the following:

> *"Delivering care to a child who is deteriorating, and who has no autonomy, privacy or independence, and which is not in their best interests is degrading and is recognised as a cause of moral distress in clinical staff."*

7. Those words must be emotionally lacerating for the parents to hear. Their views are diametrically opposed. It must be said that there is a compassionate instinct amongst all those who work with very sick children, to soothe and comfort their grieving parents. There is a recognition that grief may start long before death and that anger is an inseverable facet of grief. That anger often focuses on those most committed to help. Here, the parents have been resistant to clinical opinion and critical of it. I state that

simply as a fact without any admonition, understanding its motivation. The primary focus for the treating clinician however must be unswervingly on the patient. In challenging circumstances such as this, the views of the parents will always be important and afforded weight, but they cannot eclipse or subjugate the child's own autonomy and best interests. Grief can ambush sound parental judgement. The clinician's role is vigilantly to guard the best interests of the patient, even, where necessary, against the views of the parents. In these circumstances, emollient words and well-meaning euphemisms can be treacherous, impeding rather than facilitating a constructive dialogue.

8. Against this backdrop, Professor Playfor's unambiguous language, which initially caused me to recoil, strikes me, on reflection, as both honest and, in many ways, courageous. Paradoxically, I consider in conveying his opinion in such plain, unvarnished terms, Professor Playfor is respecting the parents' rights to have the opportunity properly to understand his views. He generates an adult exchange which is unpatronising. Moreover, these opinions are not calculated to shift responsibility for what has happened on to the parents. On the contrary, Professor Playfor directly, and Mr Karim KC, on behalf of the Trust, unreservedly acknowledge that the Trust's failure to bring this case to Court, in a timely manner, has avoidably compromised the dignity of their patient. It is a voluntary apology for a collective professional failure. This is rare and requires to be identified as such.

9. Of course, there is no freestanding test from which to evaluate human dignity. It is circumstantial and will always involve a degree of subjective perception. It may at times be elusive, but it nonetheless requires rigorous effort both to identify and evaluate. In

NHS South East London Integrated Care Board v JP & Ors [2025] EWCOP 4 (T3), I summarised the precepts set out more extensively in *North West London Clinical Commissioning Group v GU* [2021] ECOP 59:

> *"6. ...*
>
> *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;*
>
> *v. The inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination; and*
>
> *vi. Compliance with these principles may result in legitimately diverging opinions as to how best to*

> *preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry."*

The medical evidence

10. The investigation of G's circumstances has been extensive, involving treating clinicians and independent experts from a wide range of disciplines, incorporating paediatric intensive care, paediatric respiratory medicine, paediatric neurology, and clinical ward nursing expertise. Except for Dr. Simon Nadel, Consultant Paediatric Intensivist, there is a consensus amongst the respective disciplines as to G's present condition, diagnosis, and prognosis. Dr. Nadel differs, subtly, as to G's present condition, but he is in broad agreement with the prognosis. There are differing perspectives on the degree of pain and distress which G experiences within those who share the consensus. Those differences require to be identified in order properly to engage with Dr. Nadel's dissenting view, but they do not, in my judgement, ultimately impact upon the conclusion that provision of ventilatory support for G is no longer in her best interests and, indeed, contrary to it.

11. The profundity of G's brain injury has already been referred to. She has no cough or gag reflex. Though I sense the parents are unsure about it, not least because G can breathe independently for periods of time, it is nonetheless clear, in consequence of the precariousness and unpredictability of her respiratory drive, that she is entirely dependent upon mechanical ventilation (see my comments on the evidence of Dr. Ross Russell, above). The predominant view is that G is wholly unaware of her surroundings. It strikes me that Dr. Nadel does not take any significantly different view. He describes G as minimally aware, *"if she has any awareness at all"*. In common with his medical

colleagues, Dr. Nadel considers that there is no evidence that G can see or hear. In these circumstances, I do not consider it to be necessary to resolve any dispute as to whether G is in a permanent vegetative state or a minimally conscious state. What is clear is that she has a prolonged and profound disorder of consciousness in which any labelling is irrelevant.

12. G has deteriorated over time. The most obvious marker has been her loss of ability to breathe independently. Gradually, albeit from a low baseline, her general mobility and capacity for movement have deteriorated. There are additional physiological burdens associated with her underlying condition, primarily generated by her immobility and compromised respiration. These include bone disease due to osteopaenia, a secondary consequence of lack of load-bearing and the development of renal stones. She has scoliosis, which is advancing. This is common in children with severe brain disease and carries consequent cardiorespiratory impairment. She has gut dysmotility or dystonia (abnormal movement of the gastrointestinal tract, where the muscles and nerves of the stomach or intestines do not coordinate properly to move food and waste through the digestive system). G also experiences chronic airway secretion retention due to an inability to clear secretions.

13. There is no doubt that long-term ventilation (LTV) is a ‘feasible’ prospect for G. However, feasibility is not the issue. It is necessary to identify whether the treatment can be of benefit and if so, whether any such benefit outweighs the identified burdens of treatment. Dr. B, Consultant in Respiratory and Long Term Ventilation, concluded as follows, by way of a letter dated 30th January 2021:

> *"It is my opinion reviewing [G], her clinical status and progression that we should not be offering long-term ventilation with the form of a portable ventilator via her tracheostomy.*
>
> *When considering long-term ventilation for children we have to look at a number of different factors that primarily look at the ability of the child to benefit from that intervention. Long-term ventilation is not a treatment that will help improve [G]'s underlying disease and as such it has to provide benefit for [G].*
>
> *It is my opinion that she lacks the ability to benefit from long-term ventilation due to the severity of her underlying condition. Considering the quality rather than quantity of life, reviewing [G]'s clinical condition she has a severe cognitive impairment that causes her to lack demonstrable ability of awareness of herself or her surroundings and has no meaningful interaction with them. As [G] lacks that ability to derive benefit from prolongation of life it is therefore my opinion that long-term ventilation should not be offered to [G]. A reorientation of care towards comfort and support rather than life-sustaining interventions would be my suggestion."*

14. Paediatric intensive care, like its adult equivalent, is often described as providing a bridge on which a patient can cross from being seriously unwell to improvement. In G's case, that is not possible and, it follows, that the intrusions and privations of intensive care are irreconcilable with her needs. LTV, however, is not necessarily a bridge. I have been told that some patients, both children and adults, may manage for some time on LTV where they are enjoying a life from which they can derive benefit and/or pleasure, but in which there is no prospect of recovery or improvement. Mr Barnes KC, on behalf of the parents, contends that G has, in effect, been on LTV, albeit

in the PICU, for several years. He submitted that Dr. Nadel's evidence suggested that removal to a high dependency ward on LTV would significantly enhance both G and her family's life and might provide a pathway to her moving to the family home. All this depends on evaluating G's present quality of life. It is this which has been the central focus of the evidence.

15. I heard from Dr. D, Consultant Paediatric Neurologist. Dr. D impressed me as a measured and reflective witness. Her concern for her patient was obvious as was her receptiveness to questions which sought to challenge her views. Dr. D considered that G would continue to accrue morbidity, i.e. deteriorate. There is no prospect of any recovery. On this point, there is complete medical consensus, including Dr. Nadel. Dr. D, however, took a strong line on the burdens facing G were she to continue treatment and her capacity to experience distress and/or pain. She set this out in her report which she confirmed in oral evidence. These require to be recorded in some detail:

> *"109. I have spoken to several nurses during my re-assessment of G in the last two months to understand their perspective as carers. Their views are in keeping with my assessments. They report they can tell if she is asleep, as her eyes are not as widely opened then, or awake, when she also has some spontaneous movements. They report that there is generally no consistent response G makes to her daily routines except that occasionally when touched, G may stiffen her arms and legs, move her hands and feet, or move her head and neck. I had noted these movements were seen frequently without stimulus also. They do not think she can see or hear. She does not show response to pleasurable activities, such as with touch when applying topical creams, or with the tablet in front of her daily, such as by gazing or tracking, or with music or voice. They cannot tell what she is*

experiencing with potentially painful procedures such as taking blood or deep suction. They recognise responses, which are felt to be negative, such as when there are more secretions or if she has a temperature, when she would stiffen and flex her hips, or her pulse rate may increase to 150-160 beats per minute, or she may be breathing more quickly.

110. Nursing staff in PICU would ordinarily speak to inform their patients that they are undertaking interventions, such as suction or placing eye drops, which is performed frequently in G's case. If G does not see and hear, a nurse said that she "struggle(s) to think what G must be experiencing if G cannot have any warning of these interventions". I think this is an important point of view from a health-care professional who is familiar with these aspects of the caring role.

111. Her morning cares can take a long time for a single nurse to perform, and I observed that this took nearly an hour and a half once when I had to return to speak to the nurse one morning. This is due to G's muscle stiffness and contractures which make it hard to undress and dress her, as there is a risk of inflicting a fracture with simple movements even. This is a risk factor for those like G with reduced density in her bones.

112. Additionally, she has had long-standing and ongoing pressure sores particularly around her neck in various places under her tracheostomy tapes. These have received input from the tissue viability team with wound treatment plans of cleansing and dressings. This is a continued risk for G due to her limited mobility and from the added tubes and tapes.

113. As a paediatric neurologist, I would view that G has an extremely poor quality of life. If mechanical ventilation continues to be provided, I feel that this quality of life will

> *deteriorate further. I have not found any evidence that she is able to respond to any stimuli (visual, sound, tactile) and would be uncertain if she has the conscious ability to perceive these sensations. There was no evidence of G making any meaningful developmental or cognitive gains before being ventilator dependent.*
>
> *114. The question of her quality of life must also consider her ability to interact and communicate. G is unable to communicate her needs and wishes which includes pleasure or pain. I have not seen her being able to move in a purposeful manner, smile, blink to indicate she may be happy. I have also not seen her move her limbs away, grimace or frown, to indicate that something may be distressing her such as noxious stimuli from deep painful stimulus or deep tracheostomy suction despite showing other signs that can be explained by pain and distress (see paragraphs 116).*
>
> *115. It is my opinion that the burdens of treatments required to sustain G's life are significant and that they outweigh any potential benefits. This includes the numerous interventions in her daily life, as listed above, the need for invasive ventilation via tracheostomy and nasogastric assisted feeding and hydration. The burdens of her condition are unfortunately extremely limiting; in my view this impacts her vision, hearing, her ability to move, the abnormal movements and tone she has, and her ability to interact."*

16. Dr. Stefan Spinty, Consultant Paediatric Neurologist, was instructed to provide an independent second opinion for the Trust. He was clear that G has *"no or no consistent response"* in behaviour, movement or autonomically to any stimuli. This suggested to him a lack of any awareness. He concluded that G is at times awake but not alert. He

did consider it possible that she might experience some uncomfortable or indeed comfortable stimuli at some cognitive level. Reviewing what appeared to be accounts of purposeful movements by the staff (but which, it transpired, were not intended to be so), Dr. Spinty could see no purposeful movement. In his report, he said *"I have concluded that on the balance of probability, I believe that a diagnosis of "persistent vegetative state" ("unresponsive wakefulness syndrome") is appropriate"*. Later, addressing G's potential to experience pain, Dr. Spinty observed:

> *"On the balance of probability, I believe it is more likely that G is not experiencing any significant level of pain, than it is that she does. (sic) I am not able to attach a percentage number to either probability."*

17. I do not consider that diagnosis by balance of probability is appropriate here. A diagnosis of capacity to experience pain cannot be evaluated, at least in these circumstances, on a legalistic binary test. In my view, what Dr. Spinty is really saying is that whilst he cannot identify any capacity to experience pain and considers it unlikely, it cannot be definitively excluded.

18. Dr. D has direct clinical experience of the case and greater involvement with G, albeit that as a neurologist, she is remote from G's day-to-day care. Her evidence, as part of the clinical team, is more detailed and her analysis more extensive than that of Dr. Spinty, but they both come to identical conclusions. Dr. Spinty considered that *"continuing LTV will lead to prolongation of [G]'s life but without offering her the benefits of a life that would include the ability to interact, to communicate with, and to influence her surroundings"*.

19. Notwithstanding the clear view of the Trust as to where G's best interests lie, Professor Playfor, at the request of the Court, was able to set out in a detailed statement a *"Ceilings of Care Plan"* to be put in place if the Court decided that LTV was possible and in G's best interests. I recognise that a great deal of work, by a number of people, went into that document. I also consider that given the Trust felt, strongly, that such a plan was clinically inappropriate, the document reflected an open and honest engagement with an alternative perspective, which I consider is entirely free from any defence of amour-propre. It is not necessary to set the document out in its full detail; a relatively concise summary will suffice:

(i) Intravenous antibiotics would not be used to treat serious viral infections. Insertion of intravenous cannula is generally considered to be burdensome, uncomfortable or painful and restricting by children who are able to report their experience. The need for intravenous antibiotics would also signal that G's circumstances would have deteriorated. In circumstances where the criteria are met, as they are here, for *"futile care"*, there can be no benefit in such an invasive course;

(ii) No fluid resuscitation for sepsis. If G were to develop sepsis requiring intravenous fluid resuscitation, she would already be at high risk of death, and given the futility of her circumstances, such a course would be clinically inappropriate;

(iii) No inotropic support. This is essentially designed to encourage the heart's pumping ability, allowing it to deliver more blood and oxygen to the rest of the body. Manifestly, she would be in extremis and such an intervention would not be appropriate;

(iv) No intraosseous access. There can be no benefit from such a course;

(v) No renal replacement therapy. This process is similar to haemodialysis, i.e. it is a life sustaining medical treatment to take over the function of the kidneys when they can no longer work. It is deeply invasive, involving the insertion of a large central venous line into a large central vein, which is stitched in place. The provision of such therapy also carries, in itself, risk of life-threatening complications, e.g. injury to vascular and other structures, embolism, extensive bleeding, electrolyte disturbance, cardiovascular instability;

(vi) No readmission to PICU. In G's case, the view of the clinical team is that readmission to PICU is not in G's best interests as it will not positively treat the burdens of her underlying neurological condition and due to the lack of any possible improvement, fulfils the criteria for 'futile' care. She cannot benefit from readmission to PICU;

(vii) Appropriate palliative care. The focus of care should refocus from targeting physiological stability to controlling her pain and other burdensome symptoms, with the aim of improving her quality of life;

(viii) No CPR in the event of cardiac arrest. Self-evidently, in such circumstances, G would have an extremely high risk of mortality in any event. It is also important to identify that it involves chest compressions, ventilating G via her tracheostomy by bag device or by mouth;

(ix) Limitation on ventilation settings on a portable ventilator; and

(x) No high frequency oscillatory ventilation, i.e. specialised type of mechanical ventilation for critical care units for patients with severe lung failure.

20. In my summary above, I have sought to capture the ethos of the plan which is focused upon the elimination of significantly intrusive, burdensome treatments for a patient whose circumstances, all agree, can properly be described as futile.

21. For reasons which I consider to be entirely consistent with their approach throughout, the parents strenuously resist the ceilings of care plan. They believe that their daughter can win this fight. The name they chose for her reflects their belief in her robust fighting spirit.

Dr. Nadel's opinion

22. As is already clear, there is much common ground between Dr. Nadel and the professional consensus. Dr. Nadel, at the conclusion of his evidence, volunteered that his view was a difficult one clearly to express. I agree with him, but I am left with no doubt as to the sincerity of his efforts to articulate a position which is intrinsically subtle and nuanced. If I may say so, I found his evidence to be impressive, reflective and kind. It revealed a strenuous effort to analyse G's needs, not merely in the context of her complex medical circumstances but also recognising that she is a seven-and-a-half-year-old girl who has spent the vast majority of her life in PICU and whose clinical

picture must be examined through that lens. In my judgement, Dr. Nadel has healthily and robustly challenged the consensus. Cases with consequences of this magnitude are not decided on mere numbers, i.e. on how many doctors agree with the conclusion. They require careful forensic interrogation of facts, inferences, assumptions, and the underlying medical science. Factored into this must always be the recognition, as this Court has experienced in different spheres, that today's medical orthodoxies may become tomorrow's shibboleths.

23. Dr. Nadel rightfully identified that G is currently receiving minimal respiratory support on minimal ventilation settings, in air. Thus, it follows, that ventilatory support could be reproduced by a portable ventilator on the ward. Given Dr. Ross Russell's conclusion in respect of G's hypoventilation, which is at least implicitly accepted by Dr. Nadel, he recognises that there is no benefit to be gained from further attempts at weaning. It strikes me that if the conclusion of hypoventilation is accepted, then further attempts at weaning could not be justified or indeed regarded as ethical.

24. In response to Part 25 Questions posed by the parents, Dr. Nadel was of the view that G could have been moved to intermediate care at any point following her admission in 2021, that is once she had been nursed back to stability. Dr. Nadel emphasised that the ward would have been a more appropriate environment. He suggested that it might have permitted G to be more mobile and exposed to settings beyond her current windowless PICU bed space. He posited that it would have been more conducive to interaction with professionals, such as G's teachers and therapists. He was hopeful that decompression from the intensive and inevitably high-octane environment of PICU might improve the tensions between the doctors and the family.

25. Dr. Nadel focused on what he contended would be an environment which could significantly enhance G's quality of life and her family's quality of life. These two would usually be interconnected. Whether they are in fact, in circumstances where G's interaction with those around her is *"minimal ... if indeed she has any awareness at all"*, to use Dr. Nadel's own phrase, has been moot in this case. Dr. Nadel considered that G's responsiveness *"is more apparent to those who know her well and spend most time with her"*. I have found that to be a difficult observation to analyse given Dr. Nadel's own bleak professional assessment of G's awareness, which strikes me as almost the same as, if not identical to that of Professor Playfor, Dr. D, and Dr. Spinty. However, as a general proposition, I am certainly receptive to the real possibility that those who know G well and spend most time with her will be astute to nuances of alertness, which may not always have been apparent to the professionals. This general proposition, it strikes me, is somewhat watered down by the fact that G has been on PICU for so long and is so well known in the unit. I do not consider it an overstatement nor intend it to be in any way disrespectful, when I say that she has become part of the furniture.

26. It does seem to me, however, that these differences can only logically be at the margins. Thus, when Dr. Nadel states, for example, *"there is a notice at her bedside which spells out her likes and dislikes, suggesting that there is a level of responsiveness that [G] has demonstrated"*, this cannot be accepted at face value and requires to be interrogated with the same rigour that the medical evidence is. Dr. Nadel does not do this, nor was he in a position to do. However, the note jars with the medical conclusions to such a degree that I would have expected Dr. Nadel at least to signal a degree of forensic

scepticism as to what weight should be placed upon the note. As to the significance of the teacher's recordings in illuminating any level of awareness, I will turn to these below, not least because the Guardian, at least initially, placed such weight upon them.

27. Ultimately, Dr. Nadel arrived at the conclusion, which had not been trailed in his report, but was provided in response to written questions from the Trust and maintained in his oral evidence, that *"ventilatory support should be withdrawn only when G was actively dying"*. I have given this a great deal of thought, but I have come to the conclusion that this is an ethical and moral compromise which will ultimately serve nobody at all and is unworkable. Additionally, it will almost certainly lead to further litigation. Again, I emphasise the sincerity of Dr. Nadel's effort, but he is attempting to square a circle which cannot be squared, and, in my judgement, ought not to be.

28. At this point, it is pertinent to consider the Royal College of Paediatrics and Child Health Guidelines (RCPCH). In 2015, the RCPCH revised their guidelines to clinicians: **'Making decisions to limit treatment in life-limiting and life-threatening conditions in children'**. This guidance 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. In particular it describes situations in which individual children should be spared inappropriate invasive procedures—NOT types of children to whom appropriate procedures should be denied."* (Executive Summary). The Guidance defines Life-Sustaining Treatment (LST):

> *"[LSTs] are those that have the potential to prolong life…these may include… treatments such as Cardiopulmonary*

> *Resuscitation (CPR), mechanical ventilation, intravenous inotropes…"*

29. The Guidance states:

> *"The RCPCH believes that there are three sets of circumstances when 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. (My emphasis)***
>
> ***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. (My emphasis)***
> >
> > *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."*

30. It is clear that the Guidance is intended to embrace circumstances *"where death is not immediately imminent"* but where its prolongation *"confers no overall benefit"*, and situations where treatment may *"be able to prolong life significantly"* but not alleviate *"the associated burdens"*. I emphasise that the Guidance is permissive, not prescriptive.

31. I turn now to consider the evidence of Ms F, Class Teacher and Special Educational Needs Coordinator (SENCO) at the Hospital School. She has been seeing G at bedside for lessons, at a frequency of two to three times per week, during standard school term time, for a period of two and a half years. The lessons last between 45 and 50 minutes each. It is her practice to take pictures and videos to accompany her written reports. G's parents are not usually present in the lessons, which take place in the morning. Ms F told me that prior to commencing her work and throughout it, she has had no contact, nor has she sought any, with the neurologist (Dr. D). Accordingly, she has had no clinical assistance in understanding G's level of awareness. She told me in her evidence that nurses were always present with G, and that she was able to elicit their assistance. I set out below some observations made in G's End of Year Report 2025:

> *"**My communication***
> *[G] has taken part in weekly sensory story sessions. This means that familiar stories have sensory stimulus connected to each page e.g. through music, movement, resources or touch. She has taken part in stories such as 'Jack and the beanstalk', 'Swimming*

> *though the ocean', and 'Goldilocks and three bears'. [G] will use her feet or hands to explore the sensory stimulus and textures, she will move her fingers to do this and I try and let her explore as independently as possible. [G] is able to show when she doesn't like an activity, or movement as her heart rate will increase, for example [G] does not like having her head touched and she will move her head in response and sometimes stamp her feet. It is really good that [G] can show when she does not like something.*
>
> *…*
>
> ***My thinking***
>
> *During instrument exploration, [G] will move her hands on some of the instruments, to explore the sound and textures. When exploring the chimes, it only takes a small movement to get a large feedback which supports [G] exploration of cause and effect skills. She will move her left hand in the chimes for a period of time. [G] uses her feet really nicely to explore textures, she can be seen wiggling her toes, stamping her feet/ legs and moving them up and down. She recently was playing the bells and repeated movements to create a sound with the bell stick.*
>
> ***My body***
>
> *…*
>
> *[G] has been exploring cause and effect activities with the Ipad and in particular the app GarageBand. [G] has been exploring the app in different positions in her chair or in the bed. Depending on her movement that day she can make more or less sounds with the instruments. [G] has been moving her fingers on her left side to make sounds and has been repeating this motion. I have been turning the Ipad off at times to see if she continues to make movement but she either stops or, on one occasion, made a lot more movement as if she was asking 'where has the sound gone?' At the start of these sessions I play the guitar to [G] and place her hand on the wood so that she can*

> *feel the vibrations of the music, she will often still when this is happening showing listening skills."*

32. In her progress report, Ms F records the following:

"

Target	*Progress Measure*
My Communication	*Progress made*
My Thinking	*Progress made*
My Body	*Progress made*
Me and My World	*Progress made*

Progress Measure
Progress is measured for all pupils against 4 strands. Where a pupil has been identified as making some or minimal progress we have given further information.
Progress made+
Progress made
Some progress made
Minimal Progress made

"

33. I find it difficult to describe the experience of reading the above. It is a parallel reality to the world G lives in, and ironically, a poignant reminder not of what she can do but how very prescribed her life is. The videos referred to, which have been filed in the

proceedings, make what Professor Playfor described as *"uncomfortable watching"*. I have discussed Professor Playfor's candour in his use of language above; in this instance, his frankness deserted him. His discomfort, he later acknowledged, was generated by a sense that these videos, which, at least on face value, purported to show abilities which they plainly do not, inadvertently, and unintentionally, compromised G's dignity. Professor Playfor told me that these sessions brought a pleasurable experience to those working on the ward and regularly lifted the mood. There is no evidence that they were experienced as pleasure by G. Nobody who has been asked to comment on them has suggested the contrary.

34. The conventional format of the school report, indeed the whole concept of teaching a child with such a profound disorder of consciousness, requires a distortion of language and, accordingly, an inevitable deflection from the actual needs of the individual child. G is unable to 'Communicate' (the first heading in the report) or 'Think' (the second heading), nor can she explore *"cause and effect"* (the third). The evaluation of her progress in the table above is irreconcilable with her deterioration. Ms F emphasised the right of every child to an education, even those with disabilities. Very few, one hopes nobody, would disagree with this in principle. The word education derives from the Latin 'educare', which is a broad concept, embracing nurturing. I have no doubt that Ms F has a role with G and children like her. I am sure, having watched her in the witness box, that she has a great deal to offer, but it can only, to my mind be beneficial to both child and parent that it is predicated on a medically assessed baseline of the child's level of awareness. Without this, it is a journey without direction or destination.

35. When Ms F was asked about G's level of awareness, she told me that though she thought she knew when G was awake or asleep, she always asked the nurse because she was never quite confident in her own judgement. She told me that the videos were taken for educational purposes and never contemplated as evidence in the Court proceedings. As such, I think it is the use of those videos in evidence, not the fact of them, which compromises G's dignity. In response to a question from Ms Holloran, acting on behalf of G, Ms F said had she been asked to take videos for court proceedings, she would have declined. I do not for a moment doubt her integrity on this or indeed any other points. The school report she described as *"a document to share for celebrations at home"*. Delightful though that objective is, I can only see that in this case, it would serve to fuel the forlorn hopes of these grieving parents.

36. In response to questioning, Ms F was asked if she had noticed any change in G in the time that she had been 'teaching' her. I intend no discourtesy to Ms F by the use of inverted commas. Ms F described *"things"* as being very similar *"day on day"*. When asked directly whether she thought G's movements were communicative or reflexive, Ms F responded that was *"very niche"*. She said it was hard to know. She did not want to be seen as making a *"judgement"* or *"interpretation"* one way or another. When pressed, she disavowed any professional competence to draw a conclusion. She was correct to do so. She told me that the nurses sometimes commented that G's heart rate calmed when she was singing to her.

37. There can be no doubt that Ms F brought her own particular brand of sunshine into the ward and that many felt the warmth of it. I should like to think that either directly or indirectly, G felt the benefit of it too. The preponderant evidence indicates that she could not have done. In these difficult cases, it is impossible not to sense some potential

validity in instincts which are felt but which cannot be rooted either in the medical evidence or the facts.

38. For Dr. Nadel's conclusion to have secured any real traction, it would have required me to accept that the lay evidence established some level of awareness, which confounded the medical evidence. It does not, and accordingly, I respectfully reject Dr. Nadel's alternative proposals. In doing so, I would wish to emphasise that I incorporate the parents' own perceptions of G's presentation and awareness into my analysis. I have read everything that they have written and listened carefully to their evidence. Their love for their daughter is vast and palpable, but their sense of her awareness is coloured by their fathomless hope and unwavering faith.

39. Finally, I turn to the evidence of G's Guardian. Initially, she supported the parents' position. At the conclusion of the Trust's case, she changed her view, having given the evidence, much thought over the weekend. Ms Holloran's Position Statement, filed at the beginning of the proceedings, had indicated that the Guardian's position ought not to be regarded as being set in stone. In her supplemental Position Statement reflecting the Guardian's change of stance, Ms Holloran notes that *"whilst she remains of the view that there are signs that G derives some comfort from the presence of her mother, other members of her family and from positive interactions with her, she is no longer satisfied that they are sufficient to sustain her or to outweigh those aspects of her life which mean that she is suffering beyond what it is acceptable for her to bear. Given that the guardian is satisfied that there is no prospect of improvement for G there is no purpose to her suffering which the guardian can identify which justifies continuing treatment"*.

40. The Guardian visited G on five occasions, four in the presence of M. This indicates a very high level of professional commitment. In her report, the Guardian makes a number of observations concerning her own perceptions of G's awareness, recording on one occasion *"I was not expecting G's response, but she (almost imperceptibly) flickered to life. She did not turn or reach but there was a frisson of energy, or response, one would have to watch for but was very much there"*. Later, she records *"there was an energy in the bay that I was not expecting. I thought one strong thought suddenly, which was "there she is""*. In changing her position, the Guardian nonetheless emphatically stands by this part of her evidence. Accordingly, it is necessary for me to address it. For the reasons I have stated, the Guardian's observations are entirely irreconcilable with the medical evidence, nor does she have the expertise or training, as a social worker, to express an expert view on an issue of this kind, as Ms F recognised in her own evidence. It must also be said that it is rarely helpful for the Guardian to enter the factual arena.

41. I record that Ms Holloran identified, in her amended Position Statement, the following factors underpinning the Guardian's change of view:

> *"a. G's ability to react physically to such pain is significantly compromised and has deteriorated;*
>
> *b. the likelihood that this will deteriorate further leading to an increasing inability to protect herself by communicating this in a consistent way is a significant concern;*
>
> *c. the additional physiological burdens on the body but which may not be directly experienced by the patient but which nevertheless impact upon her;*
>
> *d. the impact on G of long term ventilation and the increasing stresses of treatment;*

> e. *the inevitable physical and neurological decline leading to increased burden and stresses which may not be able to be managed effectively."*

42. In her concluding paragraph, Ms Holloran submits:

> *"The guardian remains of the view that G is an extraordinary little girl who has received the very best medical care that can be offered. She is a very much loved daughter and sister and the guardian continues to respect the commitment shown by the parents to G and understands their views in relation to the application."*

43. I fulsomely agree with those sentiments. G's parents could not have shown greater love or commitment, nor could those treating her have provided her with better medical care. I hope that recognition of this can make the days ahead more bearable for both. For all the reasons I have analysed above, I make the Declaration sought by the Trust. Ultimately, I find myself clearly of the view that it cannot, any longer, be in G's best interests to provide her with ventilation which serves only to add to her burden without prospect of assisting her condition. That condition must properly be described as futile. I am satisfied on the evidence, particularly that of Dr. D, that G continues to experience a level of distress consequent on the burden of her treatment, but I also consider it important to highlight Professor Playfor's analysis, that the body can sustain physiological burden which generates strain even though the patient may not directly experience it. This latter scenario is certainly true and relevant.

Delay

44. The delay in this case provides a salutary warning. Despite the time, energy, professionalism and commitment of a huge body of people, and not withstanding the allocation of what must be a colossal level of NHS funding, G's dignity has been persistently and avoidably compromised. This should not and cannot be allowed to happen again.

45. This Trust is the same one that brought the application in *RN* [2026] EWHC 452 (Fam), before Theis J. That judgment records the following:

> *" 7. In the position statement filed by the Trust at submissions they state they are actively considering a resolution framework/protocol for similar cases, which would include, upon identification of a disagreement:*
>
> *(a) The possibility of obtaining a second opinion within a specified period.*
>
> *(b) A best interests meeting involving clinicians and family members (plans proposed by the clinicians would be circulated prior to any meeting).*
>
> *(c) In the event of*
>
> *(i) a continued disagreement, or*
>
> *(ii) a difference of medical opinion,*
>
> *an expectation is that an application would be brought.*
>
> *(d) The resolution framework/protocol would recognise*
>
> *(i) that steps should be taken to resolve the relevant issues without the need for proceedings (as outlined in the RCPCH Guidance),*
>
> *(ii) but that delay may have an effect on the child's welfare and where resolution cannot be achieved, then proceedings should be issued, and*
>
> *(iii) the importance of communication with the family throughout."*

46. In supplemental submissions before me, Mr Karim has indicated that the following is likely to be added to the protocol:

> *"Mediation… will be considered to be inappropriate when there is a disagreement in clinical opinion."*

For my part, that strikes me as a little too dogmatic. A differing opinion may provide a breakthrough in mediation. It might be better to say that 'mediation **may** be considered to be inappropriate when there is a disagreement in clinical opinion'. The point is that untethered mediation which is achieving nothing and serving only to corrode the professional / family relationship requires discipline to be imposed to reorientate the focus back on to the patient's timescales.

47. In her judgment, Theis J observed that these developments were welcome. I echo that view. I think it highly unlikely that the delays highlighted by these two cases are unique to this Trust. Indeed, I feel confident that they are not. Experience shows, in other areas of the work of the Family Court, that mediation, sensitively and skilfully conducted, can be productive and even, occasionally, transformative. Litigation, however, even when conducted in an arena which strives to be non-adversarial, investigative, sui generis, frequently polarises the parties. Thus, mediation will often be a desirable first port of call. It is not, however, unproblematic in these sensitive cases.

48. The objective of mediation must not be to achieve a compromise between the views of the treating clinicians and the wishes of the parents. In that process, the child has no voice. The objective must be to consider competing perspectives as to where the child's best interests lie. Each party must be open-minded to the views of the other, but it is the best interests of the child that must always prevail. It will never be morally or ethically

right for clinicians to yield, e.g. to a voluble parent with a dogmatic opinion, in order to move forward on a treatment plan which is perceived as 'good enough' or 'second best'. The test is *"best interests"*, nothing else will do.

49. In this case, one striking factor underpinning the delay has been the extraordinary length of time it took to achieve a second opinion, prior to considering litigation. In total, it was eighteen months. Even after it was received, nothing was done about it for a significant period. I fully understand the time, energy and expense involved in going to litigation. I am also intensely aware of the pressure on the treating clinicians and nurses that can flow from vituperative and ill-informed social media comments. These are all reasons why the Courts should strive to deal with these cases quickly and efficiently, recognising that delay at any point is usually inimical to the welfare of a child.

50. I hope it does not need to be said, though I will say it; the fact that a child may have sustained brain damaged to such a degree that they are beyond pain or awareness does not provide a defence for delay, on the contrary, it aggravates the failure. It is in respect of the most vulnerable children that all of us must be at our most vigilant to protect their welfare and their dignity.