Neutral Citation Number: [2025] EWHC 1988 (Fam)

Case No: FD24P00427

**IN THE HIGH COURT OF JUSTICE**
**FAMILY DIVISION**

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25/07/2025

**Before** :

**THE HONOURABLE MR JUSTICE HAYDEN**

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**Between :**

**Guy's and St. Thomas' NHS Foundation Trust**

**Applicant**

**- and -**

**(1) J (a Minor)**

**(2) M**

**(3) F**

**(4) Royal Borough of Windsor and Maidenhead**

**Respondents**

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**Nageena Khalique KC** (instructed by **Hill Dickinson LLP**) for the **Applicant**

**Christopher Osborne and Jamie Niven-Phillips** (instructed by **CAFCASS Legal**) for the **First Respondent**

**Ian Wise KC** (instructed by **Miles and Partners LLP**) for the **Second Respondent**

**Third Respondent** was unrepresented and attended remotely

**Michael Paget** (instructed by **Royal Borough of Windsor and Maidenhead**) for the **Fourth Respondent**

Hearing dates: 23rd and 24th July 2025

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# Approved Judgment

This judgment was handed down at 2pm on 25th July 2025 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, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

**Mr Justice Hayden :**

**The Application**

1. This is an application concerning a teenage girl (J). She is 15 years of age. The application is made by the Guy's and St Thomas' Trust (GSTT), which has responsibility for the Evelina London Children's Hospital (ELCH), where J is presently an in-patient. J is diagnosed with Pantothenate Kinase Associated Neurodegeneration (PKAN), an extremely rare and progressive neurological disorder of the brain. She suffers with Status Dystonicus, uncontrolled painful muscle spasms, which have proven to be refractory to pharmacological interventions. J has an older sister (A) who also has the same condition and suffers significant neurodisability in consequence. For reasons discussed below, the Trust seeks Declarations that it is not in J's best interests to receive 'airway manoeuvres' (chin lifts and jaw thrusts) on the basis that these have now become painful and burdensome, and that they are symptomatic treatment only, which will not treat J's progressive neurological disorder.

2. J was admitted to X in the ELCH on 12th March 2025, from the Paediatric Intensive Care Unit ("PICU") in the John Radcliffe Hospital, Oxford having initially presented to Wexham Park Hospital with worsening dystonia. J has had electrodes (Deep Brain Stimulation ("DBS") System) implanted in her brain (on 12th April 2023) to manage her dystonia. J is subject to a Care Order in favour of the Local Authority (the Royal Borough of Windsor and Maidenhead). The Local Authority is a corporate parent and shares parental responsibility with J's mother and father.

## Medical Background

3. J was referred to the ELCH Complex Motor Disorder Service for consideration of DBS on 21st March 2023. The referral was from the Acute Paediatric Neurology Service at Great Ormond Street Hospital (GOSH). DBS is a minimally invasive functional neurosurgical procedure, involving the placement of fine electrodes into the deep substance of the brain which are connected to an implanted neurostimulator device which is placed under the skin in the chest or abdomen.

4. The ELCH is one of only three services in the United Kingdom which provides a DBS service for children and receives referrals from around the country for this intervention. J, as I have stated above, has a confirmed diagnosis of PKAN, and at the point of this referral, was in a state of Status Dystonicus.

5. J experiences dystonia, a movement disorder characterized by sustained or intermittent muscle contractions causing abnormal, often repetitive, movements, postures, or both. I have been told that children and young people with dystonia may experience episodes of an acute worsening of dystonia, where involuntary muscle contractions become so severe that they may be life threatening. In themselves, these contractions are associated with an 8% risk of mortality.

6. J was first admitted to X, at the ELCH on 31st March 2023. At this time, she was receiving very high doses of a number of sedative medications, including an infusion of intravenous clonidine. She was receiving all nutrition through a nasogastric tube, and it was noted that it had been difficult to maintain intravenous access due to her involuntary movements leading to displacement of intravenous cannula.

7. In discussion with her family, both before and following transfer, the rationale for DBS was explained, and it was also made clear that this was at best a symptomatic treatment which would not in any way halt the progression of her underlying neurodegenerative disorder. The expectation was that surgery would help in resolving her then current episode of Status Dystonicus, but it was sadly inevitable that future episodes would recur. Ultimately, her condition is life-limiting. Prior to DBS surgery, J's dystonia worsened on the ward, and she was transferred to PICU as it was felt that the level of sedation she would require to maintain her comfort could only be safely delivered in the critical care environment.

8. J was transferred back to X on 20th April 2023. Post-operatively, her circumstances remained challenging. Control of her dystonia was initially precarious, with significant periods of high levels of sedation required. J experienced electrolyte disturbance, with high levels of sodium in her blood stream (hypernatraemia) due to excess fluid loss, through sweating during her episodes of severe dystonia, and treatment with intravenous antibiotics for infection. I will say more about J's responses to treatment below, but I would note here that she particularly dislikes the sweating caused by the dystonia, which plainly makes her feel persistently uncomfortable.

9. J remained an in-patient at the ELCH until 9th July 2023, at which time she was transferred to Wexham Park Hospital for ongoing care. Whilst DBS resulted in termination of the episode of Status Dystonicus, it is notable and significant that she did not return to her previous baseline, having experienced a loss of basic motor skills, a worsening of pain and discomfort due to her ongoing movement disorder, limitations

in her capacity to communicate and an increased dependence upon others for all aspects of her daily care.

10. Throughout J's admission to the ELCH, the progressive nature of her condition has been discussed with her family, who were informed, as I have noted, both of the benefits of DBS and the fact that its effect would progressively diminish and ultimately be lost over time. J was transferred back to the ELCH on 27th November 2023 for the elective insertion of a percutaneous epigastric (PEG) feeding tube. Following the episode of Status Dystonicus earlier in 2023, J had required feeding through a nasogastric (NG) tube. Whilst the surgical procedure was uncomplicated, shortly upon return to the ward, J developed a worsening of her dystonia, again entering a state of Status Dystonicus. She required DBS adjustment, and a further escalation of her already very high levels of sedative medications.

11. J was electively admitted to X at the ELCH on 22nd April 2024 for a planned overnight admission, to facilitate her one-year post-DBS Multi-Disciplinary (MD) review. It was noted on this assessment that J had experienced a further progression of her condition since her admission at the end of 2023, with the development of more obvious bradykinesia (a slowness to initiate volitional movements) and more complaints of pain related to her dystonia. She had stopped taking any food by mouth and was noted to have lost interest in even small amounts of *"taster"* volumes, as they would cause her to cough. J was only able to tolerate her wheelchair for a maximum of ten minutes at a time, remaining bed bound outside of these short periods. In this period, J was still able to smile and giggle to express pleasure and could consistently indicate a *"yes"* or *"no"* with a turn of her thumb. The positivity of J's smile and humour, along with her

conspicuous courage, has made her a very popular patient with all who have had, what they would regard as, the privilege of treating her. She is plainly inspirational to all those with whom she comes into contact. She has navigated the deterioration of her condition phlegmatically and with great resilience. However, concerns have been raised by the MD Team (MDT) recently, about signs of low mood, reactive to her deteriorating condition. A recommendation was made for some psychological support for her.

12. J was further admitted to X on 12th March 2025, from PICU in the John Radcliffe Hospital (Oxford), having initially presented on this episode to Wexham Park Hospital with worsening dystonia. She remains an in-patient in the Hospital. Against a backdrop of reported worsening dystonia and discomfort for several weeks, J had presented to Wexham Park Hospital, sadly once again in Status Dystonicus, and had been transferred as an emergency to PICU in Oxford for an intravenous infusion of high dose clonidine, a sedative medication, which could not be safely delivered on the ward at Wexham Park Hospital.

13. Following transfer to the John Radcliffe Hospital, J's DBS system had been interrogated and found to be faulty, with elevated impedances on the right intracranial seven electrode. J was transferred back to the ELCH for an urgent revision of her DBS system.

14. Dr. Y, Consultant Paediatric Neurologist with specialist interests in Motor Disorders, Neuromodulation and Acquired Brain Injuries, reviewed J on the day of admission to X and noted a significant decline in her appearance, consistent with a further progression of her underlying condition since the end of 2024. J demonstrated both more severe bradykinesia and hypokinesia (small amplitude of volitional movement)

as well as more significant dystonic tongue and upper airway movements. Involuntary movements of her tongue and upper airway were noted to cause distressing episodes of airway obstruction, resulting in acute falls in J's levels of oxygen saturation.

15. The impression of the treating clinicians at this time was that the increase of the frequency of J's dystonia was more likely to relate to a progression of her underlying neurodegenerative condition than to the malfunction noted on her DBS system, but as a potentially minor procedure could correct this fault, it was considered appropriate to attempt a repair of the system. Accordingly, J was taken back to theatre on 14th March 2025 for an urgent DBS revision surgery. Unfortunately, despite a replacement of her right intracranial electrode, the high impedances reported by the system did not improve. J was difficult to ventilate whilst under the general anaesthetic for this procedure, with significant bronchospasm (reactive narrowing of her lower respiratory tract airways) requiring high pressures to ventilate. A decision was made in the operating theatre not to undertake a more extensive DBS revision, and to transfer J to the Intensive Care Unit (ICU). She remained intubated and ventilated for this transfer.

16. J was extubated on 16th March 2025. Following extubation, she was noted to experience episodes of upper airway dystonia, requiring airway opening manoeuvres (chin lifting and jaw thrusting). J was noted to be in distress during these episodes, with a drop in her oxygen saturations, as previously noted on X. The nature, frequency and extent of these episodes have become a central feature of this case and underpin the application made on behalf of the Trust. An elevation of sedative medications, with high doses of clonidine, chloral hydrate and nitrazepam, was required, which has reduced the number of episodes.

**J's evolving medical circumstances**

17. Since March 2025, Dr. Y reports there has been a continued deterioration in J's condition, neither is there any prospect of improvement in the future. Her presentation is consistent with advanced PKAN. This condition, as I have touched upon above, is extremely rare. In evidence before me, Dr Y told me that its incidence is one in one million. It is an inherited neurological disorder. As I have said, J's elder sister suffers from it too, and is now profoundly disabled, albeit that she is faring better. The characteristic of this remorseless condition is progressive iron accumulation in the brain, leading to its degeneration. It leaves destruction in its wake: dystonia; parkinsonism; dysarthria (the weakening of the muscles required to speak); and a raft of other cognitive and psychiatric symptoms. J has now long been non-verbal. She is entirely dependent on others for every aspect of her daily care. Dr. Y summarises the current difficulties as follows:

> "*A combination of dystonia, hypokinesia and bradykinesia have limited her volitional movements to a small repertoire of facial expression and the ability to raise her thumb, though there are own limited and unpredictable periods of time in the day when she is able to perform these movements due to the high levels of sedation she is requiring to reduce the frequency of ongoing episodes of upper airway dystonia.*
>
> *Episodes of upper airway obstruction continue to occur up to 25 times a day, during which dystonia results in a blockage of [J]'s upper airway, causing significant falls in her oxygen saturation*

> *levels. During these episodes a combination of chin lifting and jaw thrusting is required to relieve the obstruction, manoeuvres which have needed to be performed continuously for up to 30 minutes*."

18. These episodes have been subject to intense forensic focus. They are described as painful, distressing and occurring with frequency. On Wednesday, the case was listed before me for Directions. A hearing was contemplated towards the end of August. I was concerned that delay of that magnitude in circumstances of this kind was entirely unacceptable. I was told by Dr. Y, who had attended at Court for the Directions Hearing (in itself an indicator of his concern for J), that the manoeuvres required to relieve the pharyngeal obstructions had been described by nursing staff as *"terrifying for [J]"*. He also told me that he entirely agreed with the description, having seen it himself. In the course of exchanges with Counsel, I came to the view that the date of the hearing should not be driven by the exigencies of the litigation but by the pressing need to consider J's distressing circumstances. If the provision of these manoeuvres was contrary to J's best interests, that could not be allowed to continue a day longer than was necessary. There was, I believe, a recognition of this amongst the professionals. In the event, I was able to call the case in yesterday with all lawyers, parties and witnesses rescheduling their commitments.

19. Between 23rd May 2025 and 9th July 2025, a Nasopharyngeal (NPA) tube was in place but with no guarantee that this would reduce the airway obstruction. During this period, J consistently indicated, by facial expressions, that she found the NPA uncomfortable, *"smiling"* when it was removed. Due to high levels of sedation and concomitant

respiratory depression, J has had episodes of a very low heart rate (bradycardia) and, therefore, increased respiratory effort. This has necessitated supplemental oxygen, delivered via a face mask. J is awake for increasingly short periods of time over the course of the day (e.g. as little as one to two hours in a twenty-four-hour period). There has been some debate about the extent of this. Her cousin (K), who visits regularly, told me that sometimes though her eyes are closed, she is merely dozing and is aware of what is going on around her. That is difficult, objectively, to evaluate, but I am inclined to think that it is accurate. K and J have a very close and loving relationship which is intuitive and instinctive. J's extensive clinical needs require her to remain on the High Dependency Ward. In addition to enteral medications, delivered via her gastrostomy tube, she receives a continuous infusion of clonidine, delivered subcutaneously. In evidence before me, K referred a number of times to the benefits for his cousin of the *"subcutaneous infusions"*, as he took care to call them, diffidently telling me how he was pleased to have mastered the phrase.

20. As stated above, the treating team have been managing the pharyngeal obstructions by chin lifting and jaw thrusting procedures. Dr. Y has described to me how the chin lifting involves placing two to three fingertips under the tip of the jaw, utilising it to lift the jaw and thereby providing extension of the neck, which serves to unblock the occlusion. Although distressing and uncomfortable, it is less so than the *"jaw thrusting intervention"*. The latter involves the placement of the flats of the hands on both cheeks, with the fingers hooked under the angles of the jaw so that the jaw can be physically pulled mechanically upwards to separate the tongue from the back of the pharynx. It is painful, whatever adjective might be used to describe it.

21. The family recognise the pain involved. Notwithstanding Mr Wise KC's submissions, on behalf of the mother (M), to the effect that the family and professionals observed different reactions, M, on this key issue, described the jaw thrusting as generating, what she described as a *"help me"* expression in her daughter's face, accompanied by a clear *"panicking"* reaction, as she described it. I do not consider those expressions to be greatly different from the description of her being *"terrified"*, proffered by the treating staff. The nurses and carers have become increasingly disturbed by the requirement of these interventions. J's reactions to them, coupled with their frequency have, for some time now, been causing the nurses and carers real distress. As Dr. Y confirmed in evidence, there has been a growing feeling that this *"can not be right"* or in J's best interests. I am told that is has been necessary to offer counselling for those undertaking these 'manoeuvres', as they have been called.

**The Palliative Care Plan**

22. On 25th March 2025, an MDT meeting was held, which was attended by a General Paediatric Consultant with an interest in Palliative Care, a Consultant in Paediatric Community Medicine, a Consultant in Paediatric Intensive care and Dr. Y, along with other members of the Complex Motor Disorder Service at the ELCH. A consensus was reached at this meeting that further DBS surgery would not be appropriate, and that it would not be appropriate to offer J further admissions to the ICU on the basis that this would not be in her best interests, given the ongoing progression of the disorder. These conclusions were relayed to J's mother and father (F) the following day, and amongst other matters, it was explained:

> *"That as an MDT we did not feel it was appropriate to replace [J]'s DBS system, as we felt that this would ultimately be futile in terms of her overall disease trajectory. I discussed that very sadly [J] had moved closer to the end of her life, and that our recommendation was that we needed to focus now on keeping her comfortable, accepting that we may need to use doses of medication which may adversely affect her breathing."*

23. In addition, it was explained that the MDT thought it would not be appropriate to re-escalate her care and readmit her to PICU. Further, it was emphasised that it would be inappropriate to reintubate or provide other invasive ventilatory support, should J's condition deteriorate. There can be no doubt that Dr. Y and this team have provided meticulous and sensitive care for J, and displayed empathy for, and sensitivity to, the circumstances of this family. If he will forgive me for saying so, Dr. Y's own sadness at the progression of this disease in this characterful and spirited young girl is visible. The family recognise this and have paid fulsome tribute to him and all those involved in J's care. M told me that the team *"had become part of [J]'s family"*. There can be no more heartfelt expression of gratitude than that. K, in his evidence, was equally and spontaneously generous, identifying one nurse, in particular, as J's favourite.

24. At M's request, a second opinion was solicited from Dr. H, Paediatric Palliative Care Consultant. Dr. H has provided a statement setting out the palliative care options. On 11th June 2025, M attended a meeting to discuss palliative care, at which Dr. Y confirmed to her that the clinical team felt *"we had reached the point where to continue to perform airway opening manoeuvres was prolonging [J]'s suffering"*.

25. The chin lifting and jaw thrusting procedures have gradually increased over time. Having started on this regime, it has been difficult for Dr. Y and all the clinical team to reassess and review the continuing appropriateness of it. It is to be stressed that this disorder is extremely rare and there is no precedent, in Dr. Y's experience, for repeated physical interventions of this kind. The procedures are undoubtedly burdensome for J. They have, as I have said, no impact on her underlying condition, which is untreatable. The level of sedation is now fixed extremely high, which also serves, inevitably and consistently, to repress respiratory effort, a familiar paradox of palliative care.

26. It has been challenging to disentangle whether the pain and distress caused to J is generated by the airway obstruction (choking) or by the manoeuvres themselves. It strikes me that it is unnecessary to seek to resolve this. The two are inextricably linked and the distress is obvious. Discontinuation of chin lifting and jaw thrusting, I have been told, will probably lead to an episode of critical airway compromise, resulting in J's death. Management of any pain and distress caused by such an episode, not relieved by airway opening manoeuvres, will require the prompt administration of sedative medications, which may, in and of themselves, fatally compromise J's respiration.

27. The treating team have considered, and I have been referred to, the Royal College of Paediatrics and Child Health (RCPCH) Guidance, 'Making Decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice'. I note that in the forward to that Guidance, Professor Cass, then President of the RCPCH, emphasises how the Guidance takes account of the broader possibilities flowing from developments in paediatric palliative care. Dr. H captures the contemporary approach to palliative care in the following passage which, in my judgement, is an important one:

> *"Palliative care is not passive; it is a proactive approach that involves identifying and addressing a wide range of needs. If symptoms arose, such as pain, agitation or secretions, appropriate nonpharmacological modalities and pharmacological agents would be used to manage these symptoms."*

28. Dr. H further describes how when a decision is made to stop life sustaining treatment and adopt a palliative approach...

> *"...the emphasis of the care moves from active/ curative treatment (which can include therapies which are painful) to one of alleviating suffering and symptom management. This does not however mean that all treatments cease, there would be the continuation of certain treatments such as feeding, repositioning, physiotherapy and suctioning."*

29. Dr. H emphasises that the approach addresses *"physical, emotional, social, and spiritual needs, aiming to enhance well-being throughout the illness trajectory"*. From considering *"quantity of life"* situation (per RCPCH Guidance), the plan moves to address *"quality of life"*. The latter arises where there is no longer qualitative benefit to continue treatment. The situation requires an analysis of the burden of the illness and consideration of the child's ability to derive benefit. Dr. H was very clear that the proposed treatment plan to withdraw jaw thrust and chin lifts was appropriate and in J's best interests, having regard to the advanced progression of her illness. All those

involved in J's treatment and Dr. H who has reviewed it independently, have come to the very clear conclusion that the proposed care plan is in J's best interests. I must also record that J's father is also unambiguously supportive of it.

## J's best interests

30. Mr Wise has emphasised the fact that J's wishes and feelings, in respect of the plan, have not been formally assessed. It is undoubtedly true that her wishes have not been ascertained definitively. She is non-verbal and, as Dr. Y says, it is difficult to see how, even with the benefit of the pictograms or other support, it would be possible to have a conversation with the degree of subtlety and nuance that her circumstances require. As I understand Mr Wise's submissions, he contends that the Trust's application should either be *"dismissed"*, as he puts it, or *"adjourned"* in order that a psychologist or some other qualified professional can work with J to facilitate her contribution to the decision-making process. With respect to Mr Wise, even if that were possible, the delay involved and the continuing burden on J would be inimical to her best interests.

31. It is important to emphasise that whilst J has not been able to articulate her wishes, she does express her feelings. Her response to the treatment is manifest: panic, alarm, terror. Recently, she has disengaged from interacting with questions concerning her health. It was thought inappropriate to try and press her, I agree. J is after all, a teenager, whose silence can also be articulate. Though he cannot be sure, Dr. Y thinks his patient is aware that she is coming to the end of her life. As he reminds us, the care that J has been receiving for her untreatable degenerative disorder has in truth, and of necessity, been palliative for a considerable period, indeed, on a proper construction, throughout the whole of her treatment.

32. The primary conduit for bringing J into the courtroom has been K, her cousin. He is a nineteen-year-old law student and an extraordinarily impressive young man. Because of her other care commitments, J's mother is only able to come into the ward once per week. The hospital facilitates video meetings for her on other days. K, who also has a part-time job to support his studies, travels across London, two or three times per week, to spend time with his cousin, J. Both their parents are cousins and K told me that J was more like a sister to him. He did not need to tell me this, it had already become obvious as he gave evidence. He tells me that J sometimes *"pretends to be asleep when she is not"*, in order to *"tease"* him. Last month, she celebrated her fifteenth birthday. I do not use the word 'celebrate' perfunctorily; I choose it with care. Notwithstanding her fragile situation, K made it a wonderful day for her. She could not partake of the cupcakes he bought for everybody, but he incorporated her into the planning and the organising of the gifts. K and the nurses festooned J's part of the ward with balloons and bunting. I have no doubt she absorbed something of the happy atmosphere around her. When her health was less compromised, J was, K told me, always very particular about whom she liked and whom she did not. She would have been selective about her guests, and so, K enlisted her in devising the invitation list. Her gifts would always be, as he put it, *"very girly"*. She was, he said, *"a girly girl"*. She enjoys the music of Taylor Swift. K laughed, perhaps with some surprise, when I described her as a *"Swiftie"*. K's delight in his *"sister"* is striking, moving and infectious. She is very lucky to have him, and he undoubtedly feels the same. K finds it very difficult to contemplate losing her. He believes that the jaw thrusts are becoming less frequent in consequence of the *"subcutaneous infusions"*. There is undoubted truth in that, but only because J now spends much of her time asleep in consequence of the sedation.

33. Mr Wise has argued, extensively, that J must be presumed to be capacitous and/or *"Gillick competent"*. If he will forgive me for saying so, he has permitted two very different concepts to elide. A child is not autonomous in the same way as an adult is, and though the views of a Gillick competent child will always be weighed into the balance, the approach to adult autonomy is different, particularly, in the sphere of decision-making in serious or life saving medical treatment issues, see: *In the matter of X (A Child) (No 2)* [2021] EWHC 65 (Fam).

34. Though there are many references in the medical notes revealing J's reaction to the chin lifting and jaw thrusts, Mr Wise alighted on a pictogram exercise, in which J had not identified these procedures as one which she *"strongly disliked"*. Into that category of choice, fell 'pad change', 'repositioning', 'dislike of heat' (Dr. Y told me that the Evelina Hospital is *"like a greenhouse"*). By contrast, 'suctioning', 'jaw thrusts', and 'holding hands' were allocated to the *"ok"* category. Some of this is not perhaps what one would have expected. What is striking, however, is that the *"strongly like"* category clearly reflects those aspects of her life that J enjoys, e.g. having her hair brushed, music therapy and, rather tellingly, the fan! K, who has been present throughout, also considered that in allocating 'pad change' to the *"strongly disliked"* category, J was reflecting an unhappiness generated by her double incontinence, about which, out of respect for her, I will say no more. Again, I am inclined to agree with K. This evidence, which requires to be placed in the broader canvass, reveals a lot about J's character and personality, but it does not bear the weight Mr Wise seeks to place on it. It cannot be interpreted as an indication that J would choose to live with her progressive

neurodegenerative disorder, in which her days are punctuated by 'terrifying' airway occlusions, necessitating traumatic interventions.

35. I agree with Ms Khalique KC, on behalf the Trust, the extent and significance of J's neurodegeneration is all too apparent. No treatment is available, and nothing can make her better. From this perspective, a decision not to provide the range of treatments (chin lifts, jaw thrusts, airway manoeuvres, replacement of DBS, CPR, intubation, ventilation, any admission to PICU for other than palliative care) cannot be equated with an active decision *"not to help"*. In this context, in *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [22], per Baroness Hale highlighted the following, which, to my mind, encapsulates the issues in this case:

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

36. I have come to the clear conclusion that to provide the contemplated treatment to J is incompatible with her best interests. The fact that M and K do not support the broad

professional consensus does not mean that I have not given careful thought to all they have said. On the contrary, as I hope this judgment demonstrates, I have listened very carefully to them. I am entirely aware of how disappointed and sad they will be by my conclusions in this judgment. It is important that I indicate that they have both played an invaluable part, with all the clinicians, in maintaining J's dignity in the face of some terrible challenges. That said, I am clear that the time has come when the treatments that have been discussed do not respect J's inviolable right to be valued, respected, and treated ethically, solely because she is J. In other words, they would not afford her the dignity that she and her family, including her *"extended family"* at the hospital, have guarded so vigorously thus far.

37. Finally, I record that J's Guardian has also supported the Trust's application.