Neutral Citation Number: **[2024] EWCOP 37 (T3)**

Case No: 14263807

IN THE HIGH COURT OF JUSTICE
COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22/07/2024

Before:

MR JUSTICE HAYDEN

- -

Between:

Whittington Health NHS Trust	**Applicant**
- and -	
XY	
(by his litigation friend, the Official Solicitor)	**First Respondent**
-and-	
ZA	**Second Respondent**
-and-	
BC	**Third Respondent**
-and-	
DE	**Fourth Respondent**

APPROVED JUDGMENT
MR JUSTICE HAYDEN

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Ms Nicola Kohn (instructed by **Bevan Brittan**) for the **Applicant**
Ms Fiona Paterson KC (instructed by **the Official Solicitor**) for the **First Respondent**
Mr Peter Mant (instructed by **Edwards Dutchie Steel Shamash)** for the **Second Respondent**

Hearing dates: 10th -11th and 16th July 2024

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Approved Judgment

This judgment was handed down at 2pm on Monday 22nd July 2024 by circulation to the parties by e-mail and by release to the National Archives.

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This judgment was delivered in public but a transparency order is in force. 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 protected party 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. The Applicant Trust seek declarations concerning XY, a 66-year-old man, who is in a state of prolonged disorder of consciousness. After extensive investigations, second opinions and independent expert evidence (solicited in these proceedings), the Trust have concluded that continued ventilation and clinically assisted nutrition and hydration (CANH), is no longer in XY's best interests. They seek declarations to that effect. Though I will return to the medical evidence, in detail, below, it is important to note that all the experts support the conclusion that drives this application.

2. XY was admitted to hospital by ambulance on the 18th December 2023. He had severe pneumococcal community acquired pneumonia. XY had an extensive history of poorly controlled type 2 diabetes mellitus, hypertension, hypercholesterolaemia and ischemic heart disease. He had a coronary stent inserted in 2016.

3. Whilst in hospital, XY suffered a cardiac arrest. Professor Hugh Montgomery, Professor of Intensive Care Medicine and Consultant Intensivist, told me in evidence that had this occurred in the community, it is highly unlikely that XY would have survived. Resuscitation attempts were ultimately successful in restoring spontaneous circulation but XY sustained multi-organ failure over the subsequent days with renal, hepatic, gastro-intestinal and cardiac dysfunction, requiring intense support, including renal replacement therapy in the form of diafiltration. In the weeks that followed and as brain swelling reduced, there was progressive improvement and stabilisation of organ function, including kidney. Unfortunately, as XY was weaned from sedation, it became all too clear that there was a significant hypoxic ischemic brain injury, manifest as seizure activity and an absence of any meaningful response to environmental stimulation.

4. The treating clinicians were also able to be effective in managing the seizure activity, which responded to anti-epileptic medication. However, as XY has emerged from coma, in consequence of the withdrawal of sedation, the treating medical team has formed the clear opinion that he does not demonstrate any features of awareness or volitional purposeful activity. This condition has been, historically, categorised as a 'persistent vegetative state'. It is a term which has been used in the case papers and in evidence, it excites a great deal of distress in families of patients in this condition. I watched as this family recoiled from the term. It has a dehumanising connotation which is, in my view understandably, perceived as offensive to the dignity of the patient. Both Professor Wade and Dr A are clear that it is not a term that illuminates anything diagnostically. These days, the consensus amongst the medical profession is that prolonged disorder of consciousness (PDOC) is a continuum which it is unnecessary, artificially, to demarcate by labels. XY, in the view of all the doctors involved in his treatment, is at the lowest point on the spectrum of prolonged disorders of consciousness. That is all they are required to say on this point. Given the wide medical consensus that I have referred to, the time has surely come to consign the phrase, "persistent vegetative state" to the past.

5. XY's children believe that their father has a greater level of awareness than do the doctors. They point to the fact that they spend many hours with him and the doctors see him much less frequently. They have taken videos which they believe demonstrate XY's capacity to respond to command by making finger movements. XY undoubtedly has the capacity for reflex reaction but the doctors do not believe that he has any sentient neurological functioning. It is important to emphasise the respectful, courteous relationship between the family and the treating clinicians. Both have spontaneously and authentically paid tribute, each to the other, recognising the sincerity of different perspectives as to where XY's best interests lie. Ultimately, XY's family hope for a degree of recovery that the medical evidence simply cannot sustain. They go further than this however, they believe in the capacity of Allah to perform miracles. They further believe that questions of life and death lie entirely in the hands of Allah and not a doctor or a judge.

6. Islam, as the family recognise, incorporates a wide range of interpretive theology. Their faith and belief however, does not embrace an alternative view, namely that XY, as the sentient person and father they knew, might already have been lost to them, at or around the time of the cardiac arrest. XY's present situation is now reduced to what has been described by Dr Bell, a Consultant in Intensive Care and Anaesthesia, instructed on behalf of the family, as a *"physical physiological existence, maintained solely by continuous medical and nursing intervention"*.

7. Dr Bell visited XY as recently as 5th July 2024 i.e., less than a week ago. He records the following observations in his assessment, which are set out in his report. Though I will not replicate them in full, I do consider it necessary to set them out extensively:

> *"3.2. He was positioned over to the right with a slight head-up tilt, being repositioned every 2 to 4 hours as part of a pressure care regime.*
>
> *3.3. He was in a state of 'wakefulness' on my arrival with eyes open, blinking spontaneously every 5 to 10 seconds, but there was no movement of the eyes or head to calling his name from either side.*
>
> *3.4. There was no evidence of any fixation on a static object or mobile light source, no evidence of visual tracking, no threat response and no evident pupillary response to light, the pupils being unequal (4 mm on the right, 3 mm on the left).*
>
> *3.7 An oral endotracheal tube was in situ and [XY] was receiving assisted ventilation in PSIMV+ mode (pressure-controlled synchronized intermittent mandatory ventilation) due to a requirement for fixed machine breaths during apnoeic episodes.*
>
> *3.8. As part of my assessment, I requested that he just received machine-assisted breaths rather than mandatory breaths, and directly observed periods of apnoea lasting between 6 and 12 seconds, occurring at intervals of between 3-15 minutes, seemingly unrelated to any degree of 'wakefulness' or external stimulation.*

3.9. Despite the significant smoking history and emergency attendance with severe community-acquired pneumonia, lung function had stabilised fairly early in this admission episode and [XY] had been maintaining oxygen saturations at or near 100% on room air for a considerable period of time.

3.12 There was no evidence of active infection at the time of my assessment and no other factor that could predictably modify the neurological picture, having confirmed prior to examination that renal and hepatic function had returned to normal after the initial critical phase (urea 4.6, creatinine 82, bilirubin 5, ALT 10, albumin 30.

3.21 Having asked [XY] during this phase of 'wakefulness' to keep his eyes closed, to follow my finger with his eyes, to stick out his tongue, to shrug his shoulders, to move arms or fingers, or to move his legs or feet, I could not determine any response, or identify any change in overall tone, facial appearance or physiological parameters to indicate any underlying frustration or distress at not being able to mount a physical response.

3.22. [XY]'s upper limbs were flaccid with a full range of passive movement possible, without any impact on facial expression or monitored physiological parameters.

3.23. [XY]'s lower limbs were held within posture restraining casts at around 20° of knee flexion, with a resting fixed flexion deformity of approximately 80° and with associated resistance to extension.

3.24. Neither forced knee extension nor sustained nail bed pressure to the feet generated any withdrawal response, grimace or change in physiological parameters.
3.25. Tickling of the soles of the feet triggered dorsiflexion at the ankle and a very limited withdrawal response of the leg but in the context of the other findings I would interpret this as a spinally-mediated reflex rather than a semi-volitional response.

3.26. Sustained nail bed pressure in the upper limbs eventually generated a minimal extensor response with the merest hint of a grimace, but no observed change in monitored parameters.

3.27. Sustained supraorbital pressure similarly generated only the most modest suggestion of a grimace.

3.28. With regards to brainstem function, a gag reflex is present on manipulation of the oral endotracheal tube with an associated minor facial grimace, and a cough reflex is present on insertion of the closed system suction catheter generating impact on or around the carina (point of bifurcation of the trachea into left and right main bronchi).

3.29. This suction process was associated with more marked grimacing and a trend towards tear production, more likely to be attributable to raised venous pressure that to distress, given the absence of any impact on the monitored physiological variables.

8. Dr Bell was very careful to incorporate family members into his assessment, specifically to evaluate whether their presence generated a greater level of responsiveness:

> *3.30. Having completed my primary assessment, I asked family members to attend to observe any potential escalation of responsiveness, but in the first instance this was compromised by [XY] entering a sleep phase.*
>
> *3.31. This was rectified as predicted by the attendant staff nurse G, by repositioning [XY] onto his left side, and I was then able to observe any potential response to family members calling to him in Bengali.*
>
> *3.32. I could not identify any movement of the head or eyes in response to such verbal stimulus, any change in the degree of wakefulness or facial expression or change in monitored physiological parameters.*
>
> ***3.33.** I then asked family members to request eye closure, tongue movement, shoulder shrug, or any movement in upper or lower limbs, with particular emphasis on finger movement given the previously submitted short video segment, but nothing was detectable by myself, family members or the attendant staff nurse.*
>
> ***3.34.** [BC], the eldest son, when asked about their perception of responsiveness, stated that tears could be generated by the presence of the grandchildren, reading of the Koran, or talk of an emotional nature, particularly at night.*
>
> ***3.35.** [BC] confirmed that no family member had ever identified any suggestion of a smile.*

9. Dr Bell concluded that A was at *"an extremely low point on the spectrum of prolonged disorders of consciousness (PDOC)"* which he considered to be entirely compatible with the hypoxic ischemic insult to the brain and the compromised cerebral perfusion around the time of the cardiac arrest on 18th December 2023. He further considered that the multi-organ dysfunction, that I have set out above, contributed to what he refers to as the *"extensive neuronal death"*, identified on the MRI scan on 16th January 2024.

10. Both Dr Bell and Dr A emphasised that XY's health was already compromised to some degree by the time he suffered the cardiac arrest in December. It seems likely that XY already had a degree of cerebrovascular disease, attributable to a very heavy smoking history, hypertension, poorly controlled diabetes mellitus and existing coronary artery disease. Dr Bell considered that this history contributed to the extent of the neuronal death and has, in turn, compromised any potential for recovery of neurological function. Dr Bell was clear that XY is extremely unlikely to make any progression on the spectrum of PDOC and will remain in his present condition. The prognosis for his survival i.e., as opposed to neurological recovery, is entirely predicated on the provision of sustained treatment in the form of assisted ventilation, clinically assisted nutrition and hydration and control of the underlying disease. He is also vulnerable to infective complications generated by the various tubes attached to him which, inevitably, breach the epithelial barrier.

> *"**4.8.** Survival from such episodes clearly depends on timely and aggressive management including expeditious source control, but if a pattern of repeated infection was to be established despite such intervention, it is increasingly likely that infection with resistant organisms including fungal species would eventually generate a picture of progressive debility with the likelihood of mortality.*
>
> ***4.9.** Given the extent of vascular pathology, [XY] is also vulnerable to further adverse sequelae of ischaemic heart disease, with the risk of sudden death.*
>
> ***4.10.** It is impossible to derive a precise prediction of life expectancy in view of all the variables in this particular case, but I would place this at 2 - 5 years with continuation of the current highest standard of monitoring and optimisation of all the major systems of the body".*

11. The family have shown the experts several video recordings which they believe to reveal evidence of a greater degree of consciousness than the doctors contend. The improvements in XY's general organ functioning, following the receding encephalopathy and returned perfusion, have also resulted in XY exhibiting reflexive responses which he was unable to initially. Understandably, the family have interpreted this as an improvement in XY's general condition. However, all the doctors are clear that this is of no neurological significance, the responsive reactions being entirely generated by the spinal cord. The increased profusion has also improved organ function which is an improvement. However, Professor Wade is also clear that on the video recordings he has seen, the movements demonstrate a reflex response of no neurological significance, generated entirely within the spinal cord.

12. The consensus amongst all the doctors, both the instructed experts and the treating clinicians, is that XY's prolonged disorder of consciousness, in consequence of his profound neurological injury, is irreversible. Dr A, whilst clear that XY is probably beyond pain, given his negative responses to pain tests and EEG results, nonetheless emphasises the burden of his ultimately futile treatment. XY has an endotracheal tube and mechanical ventilation to support his breathing. He receives nutrition and hydration via a nasogastric tube. He has no effective cough and, in consequence, requires very regular deep suctioning of his bronchi. In addition, he requires to be turned frequently to avoid pressure sores. He is provided with intensive skin management. It is a testimony to the nursing care that he has remained largely free from bedsores since his admission eight months ago, though I note that the situating of the endotracheal tube has created sores on his cheeks. The suctioning carries with it unavoidable micro aspiration which has generated infections. These have responded to anti-biotic treatment. XY is colonised with klebsiella, pseudomonas and c difficile. This has caused episodic bouts of vomiting and diarrhoea. XY is doubly incontinent. He also suffers from increased contractions to the limbs, which is an inevitability due to his inability to move.

13. For reasons which will become clear below, there has been a good deal of focus on XY's ventilatory support. Dr A has told me that XY has relatively low dependence on it, mainly relating to his apnoeic episodes. Though it is impossible to be certain, Dr A

is reasonably confident that A might manage to breathe unsupported for a period of time, possibly measured in months, if provided with nutrition and hydration.

14. Professor Derrick Wade, Consultant in Neurological Rehabilitation, has provided three reports and visited XY on two occasions, the last as recently as the 4th July 2024. He has also reviewed the videos taken by the family and attended at court. Given the high degree of medical consensus amongst all the doctors involved, which I think can properly be described as unanimous, I invited Dr A to give evidence with Professor Wade having the opportunity to comment as the evidence proceeded (the procedure known as "hot tubbing"). Professor Wade agreed that XY's organs, particularly his kidneys, have demonstrated recovery and for the reasons that Dr A indicated. He was, I think, really addressing his remarks to the family when he emphasised that unlike the other organs, the brain does not have capacity to recover. This is a concept that many families struggle with. The damaged cells are nerve cells (brain cells) known as neurons and neurons cannot regenerate. Having regard to the extensive brain injury in this case, Professor Wade concluded that the family's hope that XY could be given further opportunity to *"recover"* was entirely forlorn. Though I will turn to the family's evidence in greater detail, I would simply note, at this point, that, on an intellectual level, each of them understands the medical opinion and respects the integrity of it.

15. Professor Wade considered that continuing ventilation, artificial nutrition and hydration was entirely contrary to XY's medical best interests. He expressed himself in clear terms in his report: *"the only opportunity that [XY] is being given is for a prolonged period of dying"*. That sentence is forthright and uncompromising. I consider, however, that Professor Wade is right to express himself in this way. There is a tendency, driven entirely by sensitivity to the family, to wreathe difficult concepts in emollient language and, sometimes, euphemism. The danger in this, I am afraid, is that it risks generating confusion, misunderstanding and letting in the inevitable human tendency to filter only the perceived positives.

16. Professor Wade agreed that the video recordings demonstrated reflex and not neurological response. They are *"characteristic of myoclonic jerk, typically seen after anoxic brain damage".* Even the resting of a hand on XY's chest, he said, generated a reflex and not an emotional response. The *'lachrymation'* referred to by Dr A, perceived entirely understandably by the family as tears, responsive to either distress or happiness, he told me is also a well-recognised reflex response. Professor Wade agreed. In his second report, Professor Wade proffered a more detailed analysis of XY's experience of pain:

> *"In my previous report, paragraph 5.33, I emphasised that one could not know for certain that somebody was not experiencing pain even if they were conscious. Since then, I have researched further into pain in unconscious people. I conclude that if an unconscious person shows pain behaviours, then it is quite likely that they are experiencing pain "in the moment." It is still*

> *unlikely that they will have any recall of the pain after the event or that they will anticipate pain before a procedure.*
>
> *In this case, the reasonable probability that [XY] experiences pain when any procedures are undertaken, such as stretching a limb or applying suction to his trachea, should be considered when considering whether it is in his best interests to continue life sustaining treatment".*

17. Professor Wade is plainly not describing pain in the way that it would be experienced by a sentient patient. His description however, on the face of it, would appear to go further than Dr A's view that XY is "probably" unable to experience pain. However, on a more detailed analysis, I do not think they are saying anything significantly different from each other. Dr A said that it is always important to have the humility to acknowledge the limitations of medical knowledge. In this sphere i.e., understanding the occurrence and/or the nature of pain, he recognised that there is a dimension in which doctors simply cannot be sure. In my view, the best that can be said is that A probably cannot experience pain but if he can, it is likely to be *"in the moment"* and qualitatively different from pain as it is generally understood. In endeavouring to be precise, I emphasise that I do not, in any way, minimise the significance of this possibility. Indeed, I recognise that it weighs heavily on all concerned with XY, not least his family. Again, in wholly unambiguous terms, Professor Wade considered that both ventilation and CANH should be stopped: *"continuing with any of the interventions will prolong his life and leave him experiencing potential pain daily, all without benefit"*.

18. It is unnecessary for me to review the medical evidence more widely than the summary provided above. Professors Wade and Montgomery and Dr Bell eloquently articulate the consensus. There can be no doubt that from the medical perspective, continuation of the present treatment is contrary to XY's best interests. Dr A, who has forged a close and mutually respectful relationship with XY's family, considers that if the court were to take a contrary view of the Trust's application, he would feel obliged to stand back from treating XY. He would be unable to reconcile such a course with his clinical ethics, he would regard it as doing harm with no prospect of benefit. I emphasise that he stated his position diffidently and self-deprecatingly. He also told me that there would be other clinicians who would be prepared to take a contrary course if the court authorised it.

19. Some speculate why Judges, in cases such as this, continue to describe the decisions as challenging or difficult, when the medical evidence establishes such a definitive conclusion in respect of P's best interests. The short answer is that it is not, ultimately, the doctors or experts who determine cases. Judges are required to survey a much broader canvas of P's life than the treating clinicians are able to. Central to this is the obligation to analyse the available evidence of P's beliefs, faith and the code by which he or she lived their life, in order to establish, with as much clarity as possible, what they might have wanted, by way of treatment, if they found themselves in this parlous

condition. Every case is inevitably highly fact specific. The concept of 'best interests' is far wider than the purely medical.

The Legal Framework

20. Though the application of it, in any individual case, may be difficult, the applicable law is clear and, broadly, settled.

21. There is no evidential issue between the parties, nor could there be, that XY acks capacity to take his own decisions in relation to medical treatment. The presumption of capacity under the Mental Capacity Act 2005 (MCA) has therefore, inevitably, been displaced in this case. The court is consequently required to consider what is in XY's best interests having regard to Section 4 MCA 2005, which reads as follows:

> *"(2) The person making the determination [for the purposes of this Act what is in a person's best interests] must consider all the relevant circumstances and, in particular, take the following steps.*
>
> *(3) He must consider—*
> *(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and*
> *(b) if it appears likely that he will, when that is likely to be.…*
>
> *(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.*
>
> *(6) He must consider, so far as is reasonably ascertainable—*
> *(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
> *(b) the beliefs and values that would be likely to influence his decision if he had capacity, and*
> *(c) the other factors that he would be likely to consider if he were able to do so.*
> *(7) He must take into account, if it is practicable and appropriate*
> *to consult them, the views of— . . .*
>
> *(b) anyone engaged in caring for the person or interested in his welfare, . . .as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6)."*

22. The MCA 2005 Code of Practice provides:

> *"5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.*
>
> *5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision- maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.*
>
> *5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests."*

23. The clearest explanation of the test remains that of Baroness Hale in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67:

> *"[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."*
>
> *"[45] Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."*

24. XY's rights, protected by the European Convention on Human Rights, are engaged. In the present context, the relevant rights are established by Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for a private and family life). As the ECtHR recognised in *Burke v UK* [2006] (App 19807/06), [2006] ECHR 1212:

> *"The presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (see also its findings as to the compatibility of domestic law with Article 2 in Glass v. the United Kingdom, no. 61827/00, § 75, ECHR 2004-II)."*

25. In this context in *Aintree University Hospitals NHS Foundation Trust v James (*supra), at [22], Baroness Hale highlighted the following:

> *"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."*

26. These sentiments were re-stated in *An NHS Trust v Y [2018]* UKSC 46 at [92], Lady Black delivering the judgment of the court:

> *"Permeating the determination of the issue that arises in this case must be a full recognition of the value of human life, and of the respect in which it must be held. No life is to be relinquished easily."*

In Newcastle upon Tyne Hospitals NHS Foundation Trust v H (A Child) *[2022] EWCOP 14*, I summarised the submissions made on behalf of the child as to how the court should approach the evidence concerning pain and my conclusions in the following terms:

> *[42] Mr Davy submits that I should show "fidelity to the applicable standard of proof" and conclude that H cannot, on the balance of probabilities, experience pain. For my part, I do not consider that civil test has application in this situation. I would go further, I consider it would be quite wrong, when balancing the difficult and sensitive issues raised here, not to take account of the fact that treatment might be causing H pain. In this case, as I have set out above, the situation is further complicated by the fact that Dr Lumsden agrees that it is likely that H periodically experiences some kind of "primitive pain" reaction and discomfort. Dr Lumsden states that this is not to be equated with the pain that a sentient adult might experience. The civil standard of proof test i.e., the balance of probabilities, certainly requires to be applied in particular, and prescribed circumstances. In this context, however, i.e., in an investigative, non-adversarial, sui generis process, such a constricted approach lacks the necessary nuance. It is medically impossible to exclude the possibility of pain in H's case. There is no test, there can be, in the case of a young child, no formal assessment. The conclusions reached are based on observations alone to establish a negative i.e., what is thought not to be there. It is trite to say that this is a delicate and sensitive process. The Court's finding should reflect nothing more and nothing less than that reality when it is evaluating those factors that illuminate H's best interests. Where the doctors cannot exclude the possibility of pain, neither should the Judge.*

XY and his family

27. Though the medical profession and the family have very different opinions as to the future treatment likely to be in XY's best interests, they have, in the most difficult of circumstances, forged a genuine, courteous and mutually respectful relationship. In this

achievement, they have conferred dignity on XY's situation which, for some of the reasons I have referred to above has, on occasions, been tested.

28. XY has seven children and thirteen grandchildren. I have heard from four of his children and his wife. All the children have, at some point, been in the court room and also his youngest grandchild, still a baby, who has been impeccably behaved. XY is and has been a remarkable man. He has had an unslakeable thirst for life and a striking generosity of spirit. He was, for many years, a chef who thoroughly enjoyed his work. He took pride in the quality of the dishes he prepared. He was fastidious about the quality of his food and grew his own vegetables from an allotment which he carved from unpromising ground over many years. Many of the vegetables he grows are seeds that he propagates himself, having bought them abroad, usually in Bangladesh. The food he prepares for his family is a manifestation of his love for them. He was aware of each of his children's favourite dishes and would prepare them, unbidden, when he thought they were needed. His delight in his thirteen grandchildren has been every bit as great as that in his children.

29. XY's extraordinary generous and kind disposition was not confined to his family. His local community was central to his life and he was quick to identify and help those in need. He attended the mosque daily, frequently five times per day. His Islamic faith was profoundly important to him. I sense that his prayers were for others rather than for himself. He also did important humanitarian work providing water to remote villages in Bangladesh. It is not without poignancy that one of the central issues in this case is whether he now should be treated with hydration.

30. XY's son, M, gave the main evidence on behalf of the family. He gave his evidence orally in response to questions, the other family members read from carefully prepared letters. The family is hardworking, articulate, and suffused with the same ethical principles that they have told me about in their father. It bears repetition that Dr A has, on a number of occasions, paid spontaneous and fulsome tribute to their kindness, not only towards A but more widely and particularly to the nursing staff. They have won the affection and respect of all those caring for XY.

31. It is important that I record their views as accurately as I can in this judgment. Inevitably, not all their thoughts are reasoned or, indeed, entirely consistent. They are a family who are grieving. BC was sometimes ambushed by his emotions as he tried to tell me about the code by which his father lived his life. On the last day of the hearing, XY's wife came into the witness box to read a statement to me. She does not speak English fluently and had not intended to give evidence. M had discovered his mother writing a letter at seven o'clock that morning. She told him that she had decided that she wanted to write to the Judge. It was resolved that she would come into the witness box, read her own letter and M would translate it for her. For both, it was an emotional experience. The grief of XY's wife was almost palpable. If I may say so, sad though XY's circumstances are, he is fortunate to be greatly loved, not only by his extensive family but, as I have been told, by his wider community.

32. XY's daughter (DE) told me that the course proposed by the doctors would be contrary to Islamic faith, as understood by her father. She told me that the Quran decreed that *"he who kills a man, kills mankind; he who saves a man, saves mankind"*. This is also present in the Torah and has resonances in the Bible. Thus, it is a facet of each of the

Abrahamic faiths. All the family share this belief. By this I mean that each of them told me that A would wish to continue in his present circumstances, even if in pain, because he would have known that he would continue to provide succour to his family. I have come to the very clear view that whatever their understanding of the medical evidence might be, the loss of A is unbearably painful to this family and dominates their response. F told me that if she were in XY's position, she too would wish to endure similar circumstances to comfort her own children by her continued presence. I accept the sincerity of her statement and consider it reflected her honest position. It is argued by Mr Mant, Counsel on behalf of the family, that F's reasoning is entirely consistent with the way XY has lived his life, putting his family first at every turn. I find this to be a sensitive and well-reasoned submission.

33. Each member of the family has, as I have foreshadowed, a strong belief that XY's reactions demonstrate a level of neurological functioning that the doctors have failed to recognise and appreciate. Their belief in this is deeply rooted and entirely honest. For the reasons I have already said, it is irreconcilable with the medical evidence. The most up to date EEG (Electroencephalographic evidence) was 28th February 2024 i.e., nearly five months ago. Dr A considered this was an important piece of evidence in recording neurological and cortical response. I asked Ms Kohn, Counsel on behalf of the Applicant Trust, if it might be possible to arrange a further EEG. I am extremely grateful to them that they were able to organise it and for a report on it by Dr B, Consultant Neurophysiologist, almost immediately. Dr B reached the following key conclusions:

> *"1.1 As in previous EEGs, the majority of this EEG consists of delta (very slow) and theta (less slow) activity. This is interrupted by shorter runs of alpha range activity (moderate frequency) anteriorly.*
>
> 1.2 *These switches between fast and slow patterns happen frequently. They continue during the many trials of stimulation, but there is no consistent change between patterns at times when the stimuli are applied or withdrawn.*
>
> 1.3 *The background activity here is evidence of cortical activity, but the generally low frequency is very abnormal and suggests widespread cortical dysfunction. The lack of cortical response, in particular to noxious stimulation, carries a poor prognosis. The persistence of this slow frequency over so many months also has a poor prognosis."*

34. I entirely recognise that this report was not strictly necessary given all I have said above, in respect of the medical evidence. The conclusions illustrate that adaptive changes are not evidence of improvement or deterioration of neurological functioning. Nonetheless, the family is essentially challenging the medical view of XY's neurological function. If the responses they see are more than merely adaptive, as they believe, then that must logically point to a greater degree of neurological functioning than the evidence otherwise suggested. For this reason, perhaps mainly for them, I considered it to be

worthwhile to obtain this final piece of evidence. It is important to recognise, as Professor Wade emphasises, that the EEG report does not provide evidence as to whether A has changed significantly or whether any change is in a positive or negative direction. The EEG reveals no change. Professor Wade observes *"behaviourally [XY]'s level of response is so low that change for the worst, is probably not detectable"*. Neither does Dr B's report give definite evidence of XY's awareness or responsiveness. The EEG does not provide evidence of this. All that can be said ultimately is that the EEG does provide good evidence of how severely limited XY's level of behavioural responsiveness is. Finally, Professor Wade notes:

> *"Last, this report does not materially help in deciding on his experience of pain. Prof Montgomery felt that experiencing the pain would be unlikely. I agree that [XY] has evidence of damage to his midbrain and brainstem structures and function; for example, he needs ventilatory assistance, which indicates quite severe brainstem dysfunction. This is consistent with the hypothesis that even basic nociceptive sensations may not be experienced or perceived. The lack of any detectable response on the EEG is also consistent with this".*

35. One option that was explored at great length was withdrawal of ventilation but reintroduction of CANH after a period of intermission, required for medical reasons. I need not burden this judgment with those reasons. There is agreement that XY would not be resuscitated in the event of cardiac arrest. It was suggested that alongside this, there would be no antibiotic treatment for almost inevitable infection, consequent upon micro aspiration. I should say that this second option was contemplated by the family but I did not sense any real enthusiasm for it. Its primary objective was centred upon what XY might have wanted in the circumstances that he found himself. His inevitable death on this alternative plan would not be in consequence of a particular action by man but more easily reconcilable with his Islamic beliefs. It was not constructed as casuistry; it was a sincere endeavour to reconcile the severity of XY's medical situation with the sincerity of his beliefs. Many people would recoil from XY's present circumstances and profoundly wish to be released from them as quickly as possible. Where those wishes are identified, the Court of Protection is vigilant to promote the individual's autonomy. However, the Court is similarly obliged to promote the autonomy of those whose views many might disagree with. The essence of autonomy is the promotion of an individual's right to take their own decisions. The important proviso is whether those decisions are lawful or whether they require others to act in a way that represses their own autonomy, morally and ethically.

36. The 'alternative plan' is one that I have considered very carefully, as will be obvious to the family and indeed, to all involved in the case. Ms Paterson KC, Counsel on behalf of the Official Solicitor, highlighted an important dissonance in the reasoning underpinning the alternative plan. In their assertion that XY would have preferred to remain in this profound disorder of consciousness, from which their lies no recovery, the family have attributed to him a degree of awareness which, I have found, is not supported by the evidence. Accordingly, their view that he would choose his present situation to afford comfort to them is based on their false premise of what his situation actually is. The severe brain stem dysfunction that XY has sustained is consistent with the view that perhaps even basic pain sensations may not be experienced or perceived.

The continuing lack of any detectable response on the EEG is also supportive of this. Thus, in a very real sense, A is no longer there for his family. Grief, by its very nature, sadly, sometimes alters both reasoning and perception.

37. Having heard so much about the man XY has been, and listened to the powerful tributes paid to him, it is clear to me that the code by which XY has lived his life is predicated on principled beliefs. Those principles incorporate honesty, integrity, duty and love of his family, as well as humanity more generally. The 'alternative plan', as Ms Paterson identifies, is predicated on an inaccurate assumption. The responses that the family believe they see are misinterpretations. They superimpose upon XY, that which he cannot achieve or experience. The distortion of these relationships, at the end of XY's life, especially in such a close and loving family, runs counter to everything that each of them believes in. Of course, I include XY centrally in this. It does not sit in any way comfortably with the man he has been or the integrity that he has shown throughout his life. I do not believe, from all I have been told, that he would wish those who he has loved to believe that he was still there with them, in any meaningful sense, when the awful truth is that he no longer is.

38. I also agree that burdensome treatment of the kind contemplated here, can only be truly ethical where it can achieve benefit for the patient. Here, the treatment is futile. Dr A believes that XY is no longer receiving treatment in any real sense of the word i.e., it is not treating any condition. In short, it generates harm, not benefit and is irreconcilable with his professional oath. I entirely understand why he has come to that conclusion and for my part, in the light of my analysis above, cannot see how he could have arrived at any other. I would emphasise that his commitment to XY and his family has been unfailing.

39. Accordingly, and with the deepest of sympathy to the family, I make the declarations sought by the Trust.