



Neutral Citation Number: [2025] EWCOP 8 (T3)

Case No: 1421086T

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26/02/2025

Before :

THE HONOURABLE MR JUSTICE HAYDEN

Between :

NHS South East London Integrated Care Board

Applicant

- and -

(1) JP

(by his litigation friend, the Official Solicitor)

(2) The Royal Hospital for Neuro-disability

(3) TP

(4) VP

(5) OP

Respondents

Arianna Kelly (instructed by Capsticks LLP) for the Applicant
Fiona Paterson KC (instructed by the Official Solicitor) for the First Respondent
Katharine Scott (instructed by Bevan Brittan LLP) for the Second Respondent
Third Respondent appeared remotely
Fourth and Fifth Respondents appeared in person

Hearing dates: 13th and 14th January 2025

Approved Judgment

This judgment was handed down remotely at 10.30am on 26th February 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

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 incapacitated person 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 :

1. On 24th January 2025, I handed down judgment: *NHS South East London Integrated Care Board v JP & Ors* [2025] EWCOP 4 (T3), concerning JP, who had been in a prolonged disorder of consciousness (PDOC) for nine years. In paragraph 5 of that judgment, I indicated that I wanted to concentrate entirely on JP's best interests and return to my analysis of the delay in the case in a separate judgment. This I now do. Following a ventricular fibrillation cardiac arrest, JP suffered a severe hypoxic brain injury. JP had initially been admitted to St Thomas' Hospital, where imaging revealed an anoxic brain injury. On 21st April 2016, he was transferred to the Royal Hospital for Neuro-disability (RHN) and into the care of the Brain Injury Service (BIS). There is clear and cogent medical consensus, supported by the observations of nurses and family members that since April 2016, JP has been in a prolonged disorder of consciousness, characterised under the extant National Guidelines, prepared by the Royal College of Physicians, as "*permanent vegetative state (PVS)*".
2. It requires to be stated that, from the very early stages of his admission, there was powerful and strong evidence that JP would have hated to have been in the circumstances in which he found himself. Notwithstanding this, he has languished in this condition, as I have indicated, for nine years. His identifiable wishes and feelings, eloquently and movingly articulated by his son, daughter, brother and his partner (now deceased), either found insufficient expression or were not heard by those charged with the responsibility for his medical care.
3. JP is entirely dependent on nursing care, including the management of his double incontinence. He does not require significant medical intervention. His skin is fragile but intact, and he is at the lowest level of human awareness. The only responses he can

make are reflexive. He is incapable of purposeful movement. His movements are generated by basic spinal cord reflexes, transmitted via motor neurons. His eyes are mainly closed, opening only very briefly, often partially, in response to stimulation. Some brief abnormal extensor movement has been observed in response to pain. There is no ‘visual startle’. The validated tools of the Wessex Head Injury Matrix (WHIM) and Coma Recovery Scale (CRS-R) have demonstrated only three behaviours over a 10- minute period, the highest of which was “*eyes open for an extended period*”. This degree of neurological damage signals to the clinicians that JP is probably beyond the experience of pain, however they cannot be certain. I record that this uncertainty causes his family, and most particularly his son, continuing distress.

4. The view of both Professor Lynne Turner-Stokes, Consultant in Rehabilitation Medicine and Dr Andrew Hanrahan, Consultant Neuro-rehabilitation Specialist, is that clinically-assisted nutrition and hydration (CANH) is a ‘futile’ treatment for JP. This has, identifiably, been the case since April 2016. Alongside this are the obvious burdens of continuing treatment, which include managing his percutaneous endoscopic gastrostomy tube (PEG) and tracheostomy. CANH is received involuntarily by JP, who will have no instinct, in his situation, for either nutrition or hydration.
5. Following an application being issued, on 16th February 2024, I concluded, having heard evidence and submissions, on 13th and 14th January 2025, that it would be contrary to JP’s best interests to be provided with nutrition and hydration. I was entirely satisfied that such treatment would be futile, burdensome and, on the moving and reflective evidence of his children and late partner, not what he would have wanted. Notwithstanding the high standard of nursing care JP has received, I am driven to conclude that the failure properly to address his best interests, in a timely way, has

compromised his dignity. By this, I mean, that JP has an inviolable right to be valued, respected, and treated ethically solely because he is a human being. The inherent dignity of a human being imposes an obligation on those treating him, actively to promote his dignity. I very much regret to say that the RHN has failed to meet this most fundamental of obligations. I record that they recognise this and have made a clear and unambiguous apology, expressed to JP and his family. The importance of an apology must always be recognised, and I do not underestimate the sincerity of it. Nevertheless, in circumstances such as these, it can never be sufficient or, ultimately, satisfactory.

6. What is troubling is that some time ago in a case concerning this hospital, I encountered a very similar situation. The case was reported as *North West London Clinical Commissioning Group v GU* [2021] ECOP 59. There, I expressly endorsed the submission made on behalf of the Official Solicitor representing GU:

“as soon as there is any doubt over whether it is in the patient's best interests to continue to receive CANH, appropriate steps must be taken in every case to ensure that a timely decision is made on that issue, one way or the other. If it is not possible to achieve unanimity amongst the treating team and all those with an interest in the patient's welfare, or if it is considered that the decision is finely balanced, then steps must be taken to bring the matter before the Court, in a timely way, for a determination.”

7. In *GU* (supra), I recorded the following:

“93. Ms Walker, on behalf of RHND, has not sought to justify the delay in referring the question of withdrawal of CANH to the court. It seems to me she could not have done so. She makes a number of submissions which I record:

“RHND considers it important to emphasise at the outset of this part of the submissions that it is a charity, it is not a Trust, this has clear resourcing implications which are addressed further below. The charity was set up with the aim of giving "permanent relief to such persons as are hopelessly disqualified for the

duties of life by disease, accident or deformity," (originally called the Hospital for Incurables). RHND has always taken seriously its approach to ensuring a strong ethical position on the end of life care, and as explained at F1, this has involved the appointment until April 2018 as chair of the Ethics Committee of Laurence Oates CB (former Official Solicitor to the Supreme Court). Without diverging too far from the specifics of GU's case, RHND does consider it important to emphasise that its ethos is to provide rehabilitation and long-term care for its patients and that this coupled with the more limited experience of staff in withdrawing life sustaining treatment had an impact on its approach to CANH withdrawal cases."

8. I found the thought processes underpinning this analysis to be troubling and made the following observations:

"94. Whilst I recognise the commitment and professionalism of all involved in the RHND, I regret to say that the failure of the hospital to ensure that its ethos evolved to incorporate the very clear guidance of the Royal College of Physicians and the British Medical Association is troubling. Ms Walker amplifies her above submission thus:

"The Official Solicitor has been critical of RHND's reliance on its ethos in its representations. RHND understands why this criticism is being made, but is simply and honestly reflecting the cultural factors within RHND which meant that its policy in 2017 and 2018 did contain gaps which could lead to the sorts of delays experienced in GU's case. The policy produced by RHND in 2017 referred to the guidance produced by the Royal College of Physicians in 2013. However, RHND's policy then (and to the same extent as produced in October 2018) was a reactive one in the sense that it indicated that when it was appropriate to do so there would be discussions with the family about what options are open to them but the policy was not specific as to the processes that needed to be followed if it were not possible to obtain agreement. It is important to acknowledge this past practice and to acknowledge that RHND has been and will continue to take steps to ensure that there are no obstructions to RHND taking action. It should also be noted that a detailed Guidance and governance process (based on the prevailing National Guidance) was developed under the Policy, adopted by the RHN in October 2018 and revised in the light of experience

in March 2019. This shows a firm commitment by the RHN to properly considering and progressing cases where this was appropriate."

9. I concluded that case with a clear impression that the RHN had recognised that its prevailing ethos of *"rehabilitation and long-term care for patients"* had failed to incorporate the obligation actively to consider what their patients, with prolonged and profound disorders of consciousness, would have wanted, and properly to evaluate, in a rigorous way, where their best interests lay. The obligation to a patient has, to my mind, absolutely nothing at all to do with whether the hospital is either a Trust or a Charity. The obligation is regularly to assess where the patient's best interests lie, having regard to the broad canvas of needs, recognising that those are not limited to the purely medical. As Dr Hanrahan elegantly put it, "[JP] *is more than just his body – a tapestry of tissue or a tandem of organs*". That observation reflects the analysis of Lady 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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

10. Though I have a clear impression that the RHN has absorbed the lessons to be learned from *GU* (supra), it is also increasingly clear that the thinking (or ethos) within its institution has proved to some degree to be resistant to those lessons and to

contemporary understanding of what constitutes good practice. Dr Hanrahan has asserted that the RHN is truly committed to change, and I believe that he is entirely genuine in what he says. However, this is now the third case, from the same hospital, in a period of fewer than eighteen months, where similar failures have emerged. In *NHS North Central London Integrated Care Board v Royal Hospital for Neuro-Disability & XR* [2024] EWCOP 66 (T3), Theis J, Vice President, made the following trenchant observations:

*“92. In my judgment the ICB has an important, critical role to play. As the Clinical Lead for the ICB set out in her statement 'The ICB will undertake as a minimum an annual review of the care commissioned to **ensure that the care package remains appropriate to meet the service user's assessed needs**' (emphasis added). For these reviews to be an effective mechanism they should include active consideration by the ICB at each review to be vigilant that the care package includes an effective system being in place for best interest decisions to be made in these difficult cases so that drift and delay is avoided. The ICB should not just be a bystander at these reviews.*

93. As Hayden J stated in GU

[103] '...where the treating hospital is, for whatever reason, unable to bring an application to the court itself, it should recognise a clear and compelling duty to take timely and effective measures to bring the issue to the attention of the NHS commissioning body with overall responsibility for the patient.'...

[105] 'Regular, sensitive consideration of P's ongoing needs, across the spectrum, is required and a recognition that treatment which may have enhanced the patient's quality of life or provided some relief from pain may gradually or indeed suddenly reach a pivoting point where it becomes futile, burdensome and inconsistent with human dignity. The obligation is to be vigilant to such an alteration in the balance'.

94. The wholly unacceptable delays in GU, AB and now this case send out a blunt but clear message that such delays in

effective best interest decision making are unacceptable and wholly contrary to the patient's best interests which there is a clear statutory obligation on the responsible care providers to protect.”

11. For my part, I would fulsomely endorse Theis J’s observations, in paragraph 92 above, as to the critical role of the ICB in ensuring **“that the care package remains appropriate to meet the service user's assessed needs”** (Theis J’s emphasis). For the best interests reviews to be effective, the ICB is required to be vigilant and proactive in the process. Notwithstanding Theis J’s clear signal that they should not be *“passive bystanders”*, that appears to be what has happened again here. Indeed, at the beginning of this hearing, the ICB’s position on the Declaration sought was expressed as *“neutral”*. Given the medical consensus that had been reached at the RHN, predicated on distinguished expert opinion, reinforced by the broader clinical evidence of the nurses and family, and the high quality of evidence as to what JP himself would have wanted, I have struggled to understand the basis of this neutrality. I note that in her closing submissions, Ms Kelly, counsel for the ICB states:

“Where the ICB may be in the position of continuing to commission [JP]’s care if the court determines it is in his best interests to receive clinically-assisted nutrition and hydration, the ICB would continue not to take strong positions on the evidence...

The ICB would centre ss.4(6) and 4(7) MCA, and highlight the importance of taking into account the person’s own wishes, feelings values and beliefs, the view of those caring for the person and those interested in his welfare. In this case, the ICB would consider that:

- (a) The staff of RHND are the primary carers for [JP], and are interested in his welfare for the purposes of s.4(7) MCA;*
- b. It is apparent that his entire family is deeply interested in his welfare for the purposes of s.4(7) MCA.”*

I am left with the uncomfortable feeling that what was generating the ICB's neutrality was the fact that the entire family "*is deeply interested in [JP]'s welfare*". I have no doubt that they all are. However, the family are not making the best interests decision, nor are they being consulted as to what they think is best. Their observations are solicited to illuminate what JP's past and present wishes and feelings have been (where ascertainable), and on the beliefs and values that would be likely to influence his decision if he had retained capacity. The whole enquiry is focused on the protected party and engineered to promote autonomy for those who have lost capacity. For that reason, it is important to set out the relevant provisions in full and to emphasise that they require to be read as a whole, properly to be understood. Section 4(7) Mental Capacity Act 2005 (MCA) requires to be understood by reference to Section 4(6):

"4 Best interests

(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—

(a) the person's age or appearance, or

(b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

(2) The person making the determination 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.

(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(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—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his welfare,

(c) any donee of a lasting power of attorney granted by the person, and

(d) any deputy appointed for the person by the court,

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

(8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—

(a) are exercisable under a lasting power of attorney, or

(b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.

(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

(10) “Life-sustaining treatment” means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

(11) “Relevant circumstances” are those—

- (a) of which the person making the determination is aware, and*
- (b) which it would be reasonable to regard as relevant.”*

12. Ms Kelly continues:

“The views of [JP]’s family members are not uniform, and the weight of different family members is a matter for the court, but all of their views are relevant under s.4(7) MCA.”

Again, I emphasise that *“all of their views are relevant”* is not accurate. What is required is their views as to what JP would have wanted. Further, for the reasons that I have analysed below, the preponderant evidence pointed very strongly as to where JP’s best interests lay. The fact that there was disagreement amongst some family members does not absolve the ICB from their responsibility to evaluate the quality of the evidence. Though there will be circumstances where the Protected Party’s (P) views will simply not be ascertainable from the evidence of family, friends, colleagues, etc, the case law of the Court of Protection show these to be, perhaps surprisingly, rare.

13. In *NHS North West London Integrated Care Board v AB & others* [2024] EWCOP 62 (T3), Theis J recorded the following response to the judgment in *GU* (supra):

“64. The RHN’s Action Plan since the GU judgment has included (1) The updating of the RHN policies so they now include a structured process for both existing and new patients. There are three key stages – (i) a best interest decision (with consultation with those close to the patient by the decision-maker and the multi professional team); (ii) a second opinion from an independent expert to confirm PDOC; and, (iii) an assurance process that the requirements of the process have been met. (2) A programme of training and education has been rolled out to staff, and (3) Agreeing a protocol for how it can most productively work with the ICBs regarding timeframes and

responsibilities for various actions to ensure applications are made to the Court of Protection in a timely way.

65. Once a decision has been made to discontinue CANH or if a decision needs to be referred to the Court of Protection as there is disagreement as to what is in the patient's best interests or it is finely balanced, the case will be discussed at the weekly Executive Management Team (EMT) meetings. If the EMT are satisfied the correct processes have been followed the matter is then referred to the RHN's Ethics Committee.

66. The RHN CANH Policy was ratified by the Board of Trustees in February 2022 and incorporates the recommendations of the Royal College of Physicians set out in "Prolonged Disorders of Consciousness following sudden onset brain injury: National Clinical Guidelines, report of a working party (2020)"; and "Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent, Guidance for decision making in England and Wales (2018)". In addition, there is a supplementary policy that deals with specific more complex scenarios, a number of process maps and templates that help support the RHN CANH Policy which set out the steps to be followed, who is responsible for completing each element and a range of further material which support the process of decision making, such as a guide for families.

67. Following the implementation of the RHN CANH Policy the RHN set up the CANH Implementation Group, which both Dr Luttrell and Dr D are members of. This group met fortnightly from its inception in March 2022 until January 2024 and now meets monthly, providing oversight and review to the implementation of the RHN CANH Policy.

68. To support this work the CANH Clinical Forum was set up to support the clinical teams making these decisions. It meets fortnightly to discuss cases and review the ongoing operation of the processes and systems that are in place which can be fed back to the CANH Implementation Group. 69. Dr Luttrell's statement sets out the extensive training that has taken place for clinical staff since September 2022, which include a Schwartz round (reflective practice forum) conducted in March 2023 with a focus on CANH decision-making.

70. The work with the ICBs who commission care at the RHN is continuing with the aim of agreeing a protocol which sets out

the process for making an application to the Court of Protection in these cases, including timeframes and responsibilities for various actions.

71. As regards managing decision making for current patients as well as new patients Dr Luttrell reports that since October 2022 there have been 70 patients within the continuing care service at the RHN with a diagnosis of PDOC who are receiving CANH. Consultation in accordance with the RHN CANH Policy has completed for 51 patients. Decisions in relation to 7 patients have been referred to the ICB with a view to an application to the Court of Protection. The process is ongoing in respect of 17 patients (including those referred to the ICB) and 2 patients have died before the best interest consultation process concluded. For patients newly admitted to the RHN, consultation and best interest decisions for any incoming patients in PDOC will commence within two weeks of admission.”

14. Ms Paterson KC, acting on behalf of JP, via the Official Solicitor, submits that at the very latest, if there was an identifiable disagreement amongst the family, proceedings should have been commenced no later than 2018. Certainly by that time, there was no prospect that JP’s level of awareness could improve. The case law, beginning with *Airedale NHS Trust v Bland* [1993] AC 789 and culminating with *Re Y* [2018] UKSC 46, establishes that when a PDOC patient becomes devoid of any awareness and would, from his or her perspective, have considered such to compromise their dignity, serious consideration requires to be given as to whether continuation of treatment is in his or her best interests. It is, to my mind, axiomatic that a process which does not erect a strong scaffolding for best interests decision-taking, within timescales dictated by the patient’s circumstances, runs the serious and avoidable risk of compromising their dignity.

15. In *Re Y* (supra), Lady Hale emphasised the context of the *Bland* case, as had the speeches in the House of Lords in *Airedale NHS Trust v Bland* (supra). That was a case dealing, for the first time, with developments in medical technology. Life support systems had begun to make it possible for patients to ‘survive’ who otherwise would have died. As Lord Browne-Wilkinson observed, those “*recent developments*” had fundamentally affected previous certainties about what was life and what was death. The case confronted the now persistent reality that the time and manner of someone’s death might no longer be dictated by a natural event but might instead be determined by human decision. Each of the speeches recognised the wholly new social and ethical landscape raised by these developments and candidly acknowledged the reality then, as now, that people’s views differed widely. The decision in that case, to uphold the Declarations made by Sir Stephen Brown (P), was made on a carefully crafted and narrow basis, predicated on the facts of the instant case.
16. In *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169, King LJ made helpful, obiter remarks about the reality of what now happens in practice, some thirty-four years on from *Bland* (supra):

“26... *In reality virtually all of these traumatic decisions are made by agreement between the families and the treating teams of the person involved. To suggest that every case should go before a judge (even where all concerned are in accord as to what was in the best interests of the patient) would not only be an unnecessary pressure on the overstretched resources of the NHS trusts and add to the burden on the courts but, most importantly, would greatly add to the strain on the families having to face these unimaginably distressing decisions. In my judgment, the practice direction provides valuable procedural guidance but should not be interpreted as introducing a requirement that all cases where a decision is to be made about the withdrawal of CANH must come before a court.*”

17. That passage bears repetition. In the courtroom, and perhaps more generally, it is too easy to forget that these sensitive cases, which are frequently highly emotionally charged when they come before the court, are the exceptions. Most of these sad decisions are now taken collaboratively by families and doctors, each respectful of and sensitive towards the other. Both from their differing perspectives, and sometimes with different conclusions, are endeavouring to identify the best interests of P. Over the three decades since *Bland*, society has learned and is continuing to learn how to navigate the moral and ethical dilemmas which arise in consequence of advances in medicine. As the case law shows, these decisions must be approached carefully and holistically, keeping P's needs at the centre of the process. These decisions weigh heavily on all involved. It is almost trite to say that they require careful thought, reflection, and a holistic survey of a broad body of information. Equally, avoidable delay will invariably be inimical to P's interests. It is this last consideration which has proved to be such a challenge to the RHN.
18. It is important to say something of the relevance and weight to be afforded to the views of family members, when evaluating best interests. Grief, which does not await death, frequently ambushes families in these challenging circumstances. Sometimes, their own sense of loss can become the prevailing emotion. This is of course entirely normal and natural. Those charged with the task of identifying what P would likely have wanted must be alert to the reality and focus of their enquiry. The views of family members, their own wishes, feelings, religious and cultural beliefs, are, in themselves, of little, if any, relevance. I emphasise that their views are being sought solely to illuminate the likely wishes and feelings of P. Their evidence is garnered to assert P's autonomy, not to subjugate it. This case is, as my earlier judgment seeks to demonstrate, a striking

example of this point. To some extent, many of the family members here identify as Pentecostals, certainly many have strong Christian faith. Their views, however, on these difficult ethical issues vary widely. I have placed emphasis on the evidence of those family members who have eschewed their own religious and cultural views and concentrated on the views and beliefs of JP.

19. It is clear that the RHN recognised these different views within the family. The immediate family, to use Ms Paterson's helpful term, all held clear views that continuing treatment was entirely contrary to what JP would have found tolerable. For the reasons set out in the earlier judgment, those views were expressed cogently and were supported by substantial and choate evidence. Those family members, believing that their father was beyond any experience of his surroundings, eventually drifted away from the hospital and turned, as they had to, to their own lives and young families. VP (JP's daughter) told me, expressly, that she stopped attending the hospital with any frequency because her father was "*no longer there*". The wider family, perhaps in part driven by moral and religious obligation, as well as love, continued to attend. I suspect, and I say this without any criticism at all, that their views became heard most clearly and consistently. I have found that those views were not JP's.
20. With no apology for further repetition, because the point needs to be crystal clear, the objective of the discussions with family members is **not** to ascertain their views and beliefs but to ascertain if what they have to say can illuminate P's wishes and beliefs. There has been some discussion as to the need to be sensitive to "*the family's views*". This referred to JP's sisters' and mother's strict religious beliefs. Of course, I would expect all concerned to be respectful and polite, and I have no doubt they were. However, delaying decision-making for JP in consequence of a heightened sensitivity

to the religious views of some of his family would be to neglect him and to lose focus on the central question of what is in JP's best interests. The incapacitous individual, with no awareness of the outside world, is uniquely vulnerable and requires vigilantly to be protected.

21. It was clear from Dr Hanrahan's evidence that he was convinced from the beginning, and particularly after his conversation with JP's partner, that JP would not have wished to languish as he now has done. There was strong and convincing evidence as to what JP would have wanted from the outset. I have struggled to understand why there was not a timely application to the Court. I have not discovered any satisfactory explanation. Dr Hanrahan did not seek to proffer one. It is important to say that when there is disagreement within a family as to where P's best interests lie, that is a signal to bring the matter to Court. It most certainly is not a reason to spend months or, as here, years in hand-wringing procrastination. Moreover, the divide in the family really lay between those who had drilled deeply into the beliefs and codes by which JP led his life, and those who advanced doctrinal objections. Keeping JP at the front of the process and applying the best interests test in the manner required, has, on a proper analysis, indicated throughout, that the evidence of the former is qualitatively strongest. A failure to act when confronted by a family disagreement is to elevate that dispute above the best interests of the patient. It is also necessary to say that where the focus is, as it must be, on what P would most likely have wanted, and where there is a reliable foundation (as here) to establish what those views are, it is not helpful or in P's best interests to spend months tracking down family members whose addresses are difficult to find. The exercise is a proportional one, predicated on the quality of the available evidence and the undesirability of delay.

22. It is pertinent to note that the issue of CANH was directly confronted with TP (JP's son) during a telephone discussion on 27th May 2022. Whilst TP, with what I find to be characteristic integrity, highlighted that other family members took a different view, he was very clear that his father would not have wanted it and explained his reasons. I can find no evidence that the RHN acted on his concerns which, objectively, on the medical evidence, they must, by this stage, have shared. They were aware that their patient had been in what they term to be a permanent vegetative state (PVS) for nearly five years by this point, and they were fully familiar with the case law and, of course, my own comments about the RHN practice, made in *GU*.
23. Ms Scott, on behalf of the RHN has told me that the response of the hospital to my judgment in *GU* was "*profound*". It is, I hope, clear that I acknowledge that there has been a determined professional commitment to correct their approach to reviewing continuation of CANH. Ms Paterson also recognises the extent of this commitment. However, this case and the two others heard by Theis J, signal that the attitudinal sea change required is not yet complete. The following passages from Ms Scott's closing submissions indicate the extent of the work that has been done. It is important that this is reflected in this judgment. The system that has been devised is thought-through, robust and sensitive:

"6. The impact at and on the RHN of the judgment in GU was profound. It became immediately apparent that the RHN needed to reform wholesale its approach to reviewing whether CANH continued to be in the best interest of its residents and patients. This necessarily required the RHN to do significant amounts of work to put in place a robust system of best interests consultation and decision-making which could be rolled out for all of its patients and residents receiving CANH, before it could begin to undertake the best interests consultation and decision-making process in respect of any of its individual patients. The risk of not putting in place appropriate structures and systems was that

best interest decisions with the patient 'firmly at the centre of the process' would not be possible. This work included:

(a) Drawing up policies and procedures for best interest decision-making, to ensure that each best interest decision was made in accordance with the law.

(b) Identifying staff who could undertake the consultation process with the family members (and others with an interest in the patient's welfare) as mandated by s.4 of the MCA. The RHN is a charity. It is independent of the NHS. It does not have a wide pool of staff upon which it can draw.

(c) Training up those staff to carry out the best interest consultation in accordance with the RHN policies.

7. The RHN therefore:

(a) Immediately began a period of consultation with clinical leaders in the RHN about a CANH policy. By February 2022, the CANH Policy had been finalised and ratified by the Board of Trustees.

(b) Established a CANH Implementation Group in March 2022, to ensure that all patients in PDOC have a clearly recorded decision about their best interests in relation to CANH. A dedicated PDOC Lead was appointed, dedicating two days a week to the function. The group met fortnightly until January 2024, when it reduced its meetings to monthly.

(c) Instructed wards and clinical teams to identify any patients in PDOC receiving CANH for whom a best interest decision would be required. The RHN did not have the resources to initiate best interest consultation processes for all patients within that cohort simultaneously. Therefore, the teams themselves then needed to identify the order in which best interest decision making within the eligible patients would take place. Generally those patients whose family/friends had expressed concerns about whether the patient would value their current quality of life were commenced first.

(d) Embarked (in September 2022) upon a comprehensive programme of staff training. More than 300 clinical staff members (nurses and doctors) have participated along with a further cohort of health care assistants and colleagues from Royal Trinity Hospice. This training offering is ongoing.

8. The Court is asked to note that all of this work had to be undertaken while staff (emerging from the pandemic), were continuing to care for their patients, many of whom require very specialist care.

9. With respect to the 70 patients in the specialist nursing home part of the RHN who had been identified in October 2022 as being in PDOC and in receipt of CANH:

(a) Consultation has concluded in respect of 58 of the 70 patients. Of these, agreement could not be reached as to what was in the patient's best interests for 7 patients and these decisions have now been considered by the Court of Protection.

(b) For 9 residents, the best interest consultation process is ongoing.

(c) 3 of the residents either died or were discharged from the RHN prior to a best interest decision being made."

24. Bearing all of the above in mind, it is easy to see why, as Dr Hanrahan told me in evidence, JP found himself towards the top of the list in this new regime. Discussions began on 27th May 2022. Ms Scott has provided a chronology of the consultation process which she describes as *"not straightforward, made more complex by the size of JP's family and the fact that many did not live in the UK"*. Ms Paterson, whilst deprecating the delay on behalf of the Official Solicitor, suggests that those delays *"need to be set in the context of the unusually tragic circumstances of JP's immediate family leading up to his partner's death in 2022 and the Covid-19 pandemic, in which hospital services were disrupted for almost two years"*. Ms Paterson concludes: *"the Official Solicitor suggests that the Court should not lose sight of how the circumstances faced by the immediate family and the pandemic almost certainly played a significant part in the delays in the RHN's decision-making"*. I accept everything that is said there but it does not come close to justifying delay of this magnitude. In any event, as Ms

Paterson emphasises, the starting point for analysis of the delay from JP's perspective is not May 2022 but sometime in 2017. Ms Paterson submits:

"The Official Solicitor suggests that the court endorses the ICB's concession that it ought to have reviewed "the overall appropriateness of [JP] continuing to receive life-sustaining treatment" and the "[new] system in place at RHN for newly admitted patients" which, if applied to [JP]'s case, would, arguably, have resulted in proceedings being issued in 2017."

I consider this submission to be fully made out and conclude that it cannot be resisted. Indeed, I do not believe any party has sought to do so. I recognise that it will be painful for JP's children to read this, and I should like to reassure them, as I did in my earlier judgment, that their response to these challenging circumstances has not only been unimpeachable, it has been inspiring.

25. I do not consider it necessary to burden this judgment by picking through the chronology of the delay. That is an unnecessary exercise. The extent of the delay tells its own lamentable story. The Official Solicitor has drawn my attention to Parliament Postnote 674, July 2022 which states that there were *"between 4,000 and 16,000 patients in VS in nursing homes in England and Wales, with three times as many in MCS and an unknown number of people with PDOC care in other settings"*. Ms Paterson highlights what she terms *"the correspondingly modest number of applications issued to the Court of Protection regarding PDOC patients"*. She infers from this that *"there may well be significant numbers of PDOC patients in nursing homes across England and Wales in respect of whom a full consideration of their best interests has not taken place and that the delays seen in this case may well be far from unique to the RHN"*.

26. These troubling statistics may be rooted in several explanations. I do not consider it appropriate for me to speculate on the potential “*multi-factorial*” reasons that Ms Paterson posits. I do, however, see force in the Official Solicitor’s suggestion that the relatively early discharge of PDOC patients from both an acute hospital or a brain rehabilitation service to a General Practitioner or nurse led community-based service may be a significant feature. As Ms Paterson says, the reality is that P is moved from an environment in which they have been reviewed regularly by a clinician with specialist knowledge (e.g. neurology or neuro-rehabilitation) to an environment in which medical reviews are performed by a General Practitioner review most frequently generated by symptoms or medical problems separate from the prolonged disorder of consciousness.
27. The consequence of this, Ms Paterson submits, is that the “*constant and unswerving focus*” on P’s best interests (a reference to my phrase in *GU*) is “*undertaken by nursing, occupational therapy and speech and language therapy staff, with whom, in most cases, the patient will have daily contact*”. Where we are dealing with such profound and prolonged disorders of consciousness, there is a more limited scope for occupational and language therapy. The reality, therefore, is that the patient’s primary and frequently only daily contact will be with nurses.
28. I have already commented on the exquisite standard of care that the nurses at the RHN provide. I recognise the physically demanding nature of this care, as well as the emotional challenges for nurses caring for patients who have no, or very little, awareness of their surroundings and no prospect of any recovery. The required consideration and review of whether CANH continues to be in P’s best interests may not always sit comfortably with the nursing role. The responsibility of evaluating

whether CANH continues to be in a patient's best interests may be counterintuitive to a nurse who dedicates many hours to a patient's physical care and who is vigilant, as these nurses so manifestly are, to the protection of their patient's dignity.

29. The assessment of best interests is uniquely sensitive in these challenging circumstances. By way of illustration, I think JP's physical deterioration, which was so striking to Dr Hanrahan when he visited, not having seen him for some time, may not have been as stark or as obvious to a nurse for whom the deterioration had unfolded slowly and progressively over months. Moreover, as I have suggested, the obligation regularly to assess whether CANH continues to be in a patient's best interests may not find any real expression in the ethos of those providing primary physical care for PDOC patients. I emphasise this is not to be critical in any way, but it is a recognition of the objectives of essential nursing responsibilities, which do not ordinarily contemplate assessments of this kind. It requires to be stated that the decision for the nurses, along with the General Practitioner, is whether to generate a multi-disciplinary assessment of whether CANH continues to be in a patient's best interests. It strikes me that both the General Practitioner and the lead nurse must recognise this both as a joint responsibility and one which is integrated into their respective obligations to the patient. I recognise that this requires special training.
30. The present BMA Guidance, published in 2018 (Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales), remains instructive:

"a. At page 23: 'Discussions about best interests should begin at an early stage and, in some cases, may continue over a significant period; this process is likely to involve both informal discussions and sharing of information, and formally recorded meetings. The aim is for the clinical team and those close to the

patient to share clinical information and information about the patient, so that the decision-maker has sufficient knowledge about the patient to make a judgment about whether CANH would be in the patient's best interests.'

b. At page 32: How wide the consultation should be will depend on the individual circumstances and the consequences of the decision being made, and it is for the decision-maker to make that judgment. Speaking to a range of family members and friends, however, as well as others who may have an interest in the welfare of the patient, helps to protect against intentional or unintentional bias and gives the decision-maker a broader view of the patient's life, personality, feelings, beliefs and value. As a result, it increases the chance of obtaining sufficient information to be able to reach a decision about whether CANH would be in the patient's best interests.

c. From Appendix 1 – practical guidance for best interests decision-making at page 57 states 'How extensive this consultation should be will depend on what is 'practicable and appropriate' in the individual circumstances and should be proportionate to the consequences of the decision being made. Where someone has suffered a sudden-onset brain injury, but is otherwise healthy, more consultation will be needed. The nature and complexity, of the family relationships may also be relevant factors in this decision. The person responsible for making the decision should ultimately decide how wide this consultation should be.....

For the most significant decisions, it is important to ensure that attempts are made to identify all relevant people to be consulted about whether CANH would be in the patient's best interests. so it is important to look beyond the immediate family to gain as much information as possible to feed into the decision making process. Identifying those who can contribute this information – and ensuring that a range of views is heard – can be difficult.

Seeking views from a number of different people and seeking examples or evidence to back up statement made, or views expressed, is a good way of testing the information provided and ensuring that decisions are focused on what is in the best interests of the patient, not in the best interests of others.

d. Page 59: 'Discussions about whether it is in the patient's best interests to receive or to continue to receive CANH can be

challenging and complex, and require sensitivity. This is particularly so where the patient has been receiving CANH for a long time and it is the primary form of life-sustaining treatment being provided.”

31. In analysing the delay that has occurred, the ICB acknowledges that JP’s case should have been identified and referred to the Court of Protection sooner. They have apologised for their part in that delay. It is important that I record their response:

“Avoiding delays of this nature in the future

6. The ICB recognises that as a commissioner of care, it must give active consideration to whether the ‘care package includes an effective system being in place for best interest decisions to be made in these difficult cases so that drift and delay is avoided,’ as stated in XR. NHS CHC reviews are conducted on at least annual basis per the national framework, and the ICB did review [JP] annually during this period save for one year during the pandemic. The ICB has reflected on the lessons in [JP]’s sad case, and recognises the need to be proactive in exploring if there are other patients within the South East London population living in similar circumstances. The ICB will, as a priority, work with system partners across to identify and review patients on a case-by-case basis to determine whether care of this nature is agreed to be in the patient’s best interests, or agreed not to be in the patient’s best interests, or whether there is a need for the Court of Protection to determine any relevant dispute. The ICB is conscious that this would be needed both for patients in a hospital setting and for those patients who may be residing in nursing homes or in the community.

7. Since its formation in July 2022, the ICB has worked on developing the governance, escalation and oversight mechanisms for complex and high-risk patients that the ICB funds care for. This includes any patient where there is an element of safeguarding concern or mental capacity that should be considered. There is currently a suite of refreshed policies and procedures (most likely the Clinical Quality Assurance and Safety framework and protocols) going through the ICB internal

governance processes to ensure greater alignment and standardisation across the ICB.

8. The ICB is aware that some of its system partners have already taken proactive action in relation to the identification and review of any patient who may lack capacity based on profound brain injury and prolonged disorders of consciousness. The ICB will continue to collaborate and assure that this work has been undertaken using a consistent approach across South East London.

9. Following the escalation of [JP]'s case to the ICB's Chief Nursing Officer we will also be undertaking An After Action Review to identify areas of improvement and gaps in policy, procedure and approach across the system and the wider regional health economy that will need to be addressed.

10. The ICB anticipates that relevant training based on its findings will be delivered to all partners across the South East London System."

I have re-read these passages several times. I should very much have preferred plain language, an unambiguous recognition of the extent of the delay, and acknowledgment of the avoidable pain caused to the family by it. I am prepared, however, to take the assurance that *"there is currently a suite of refreshed policies and procedures (most likely the Clinical Quality Assurance and Safety framework and protocols) going through the ICB internal governance processes to ensure greater alignment and standardisation across the ICB"* as an expression of a real determination to ensure that the ICB will not in future be a *"passive bystander"*, to use Theis J's apposite phrase. The obligation is to be a proactive participant in promoting the patient's best interests. I note, as has the Official Solicitor, that the review of the ICB's working practices would appear to be at a relatively early stage. For all the reasons set out, and which I am bound to say strike me as obvious, this review requires to be given priority. What has occurred with JP is entirely unacceptable.

32. Ms Paterson submits that in deferring their obligations to the RHN, the ICB may have leant too heavily on the status of the RHN as an internationally recognised centre for neuro-rehabilitation. I have some sympathy with that but, to use the famous aphorism of human fallibility, *‘even Homer sometimes nods’*. The checks and balances required to ensure that these crucially important decisions are taken effectively and timeously are predicated on robust collaborative relationships. The law relating to decisions to discontinue the provision of artificial nutrition and hydration in PDOC cases is now well settled. Neither is there any lack of clarity in ascertaining what procedural steps need to be taken by the parties, collectively to ensure that an application is ready for a hearing when one is required.
33. Ms Paterson has also highlighted what she describes as the RHN’s drift *“into a well-meant attempt to mediate the family dispute about [JP]’s best interests, which resulted in yet further delay”*. She makes the following submission:

“The Official Solicitor suggests that a clear signal needs to be sent through the judgment that there is no onus on either ICBs or healthcare providers to broker an agreement between family members, even if that would be desirable. The terms of section 4(6) of the Mental Capacity Act 2005 only place an obligation on a decision-maker to take “reasonable” steps to “ascertain” P’s wishes and feelings; and, s4(7), to “take into account, if it is practicable and appropriate to consult them, the views of anyone engaged in caring for the person or interested in his welfare”. In light of this, in the present case, it would have been better to file an application, once the immediate family had been consulted and the family tree obtained from [TP]. That said, the need for an application definitely crystallised once either the RHN and/or the ICB had been met with the absence of a response from a family member(s) as there was then “a lack of agreement as to a proposed cause of action” in relation to “the provision of life-sustaining treatment.”

34. I would endorse this submission. There is no onus on the ICB or healthcare providers to broker an agreement between family members. Ms Paterson moots that it might be desirable if there were. On that point, I take a stronger view. That approach risks occluding the nature of the enquiry, which as I have been at pains to identify, is directed towards understanding what P's wishes and feelings might have been in these circumstances. It is difficult to see how a disagreement amongst those consulted is capable of mediation. The question is ultimately a binary one: would P have been likely to prefer to remain artificially nourished and hydrated or would he have preferred it to be discontinued in circumstances where treatment was ascertainably futile. Mediation in these circumstances risks conflating the family's views of best interests with the authentic views of P himself.
35. Perhaps the loudest signal emerging from this troubling raft of cases is a failure to understand the crucial significance of issuing proceedings promptly. The Official Solicitor suggests that it is better for an application to be filed early, with an accompanying report by a General Practitioner and, if necessary, stayed for a short period while a second opinion from a Consultant in Neuro-rehabilitation is obtained. The reasoning underpinning this is to ensure the Court is seized of P's best interests as early as possible. Equally importantly, P's voice will be given the priority it requires by the provision of representation that this would confer. This, it is said, ensures that "*in effect, the court proceedings and the ICB's and/or the healthcare providers' compliance with the guidelines can be progressed in tandem, but P's best interests remain at the forefront of any "time-tabling".*" I find this an attractive submission, but I would not wish to be quite as prescriptive. It seems to me that the spirit of this could or ought easily to facilitate a timely application with both the General Practitioner report and one from a Consultant in Neuro-rehabilitation.

36. Finally, the circumstances here have made it necessary for me to be critical of failures in the decision-making processes and the lack of appreciation of the collaborative nature of the obligations involved. I should like to make it clear however, that I recognise in this case, as in so many others, that the individuals involved are each highly motivated to do their professional best in what are immensely challenging circumstances.