Neutral Citation Number: [2024] EWCOP 66 (T3)

Case No: COP 14234849

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 14 November 2024

Before :

MRS JUSTICE THEIS SITTING AS THE
VICE PRESIDENT OF THE COURT OF PROTECTION

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Between :

NHS NORTH CENTRAL LONDON INTEGRATED CARE BOARD — **Applicant**

-

and –

ROYAL HOSPITAL FOR NEURO-DISABILITY — **1st Respondent**

- and –

XR (by his litigation friend, the Official Solicitor) — **2nd Respondent**

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Ms Claire Watson KC (instructed by **Hill Dickinson LLP**) for the **Applicant**
Ms Katie Scott (instructed by **Bevan Brittan LLP**) for the **1st Respondent**
Mr Michael Horne KC (instructed by **the Official Solicitor**) for the **2nd Respondent**

Hearing date: 14th October 2024
Judgment: 14th November 2024

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JUDGMENT

This judgment was handed down at 10.30am on 14 November 2024

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This judgment was delivered in public but a transparency order dated 14 November 2024 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 XR 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.

Mrs Justice Theis DBE :

Introduction

1. In December 2017 XR, now aged 62 years, suffered a severe hypoxic ischaemic brain injury following an out of hospital cardiac arrest secondary to a myocardial infarction. Following treatment at an acute hospital XR was transferred to the Royal Hospital for Neuro-disability (the RHN) in May 2018, where he remains.

2. XR has been assessed to be in a prolonged disorder of consciousness (PDOC) at the lowest end of the spectrum of awareness, namely a vegetative state (VS). XR shows no awareness of his surroundings, he is unable to communicate and requires 24 hour care. The medical evidence is agreed that his condition is permanent with no prospect of recovery.

3. The NHS North Central London Integrated Care Board (the ICB) issued these proceedings on 9 April 2024 seeking a determination under the Mental Capacity Act 2005 (MCA 2005) that it is lawful and in XR's interests for those treating him not to continue clinically assisted nutrition and hydration (CANH) through a percutaneous endoscopic gastrostomy (PEG) tube and to provide palliative care only. The matter was originally listed in July 2024 but was adjourned on the application of the Official Solicitor for further evidence to be filed.

4. XR's lack of capacity is not in dispute, so the focus of this hearing has been on what is in XR's best interests.

5. There has been a delay in a best interest decision being made for XR due to the lack of an effective system for such decisions being made at the RHN. In *NHS*

North West London Integrated Care Board v AB & Others [2024] EWCOP 62 I considered the delays in such decisions in some detail. I do not propose to repeat what is set out in paragraphs [60] to [73] in the *AB* case. Those observations apply equally in this case. A different feature here is that XR has not been visited since 2018 and has no known family or friends who can provide details as to his wishes, feelings, values and beliefs.

6. In the statement filed by Dr Luttrell, Clinical Director at the RHN, he acknowledges that following XR's admission to the RHN in 2018 there was no formal process for best interest reviews as to whether CANH should be continued. He accepts that the best interest consultation process did not commence until Spring 2023 as a result of the systemic review undertaken by the RHN following *North West London Clinical Commissioning Group v GU* [2021] EWCOP 59. In his statement Dr Luttrell outlines the chronology from then until April 2024 when this application was issued.

7. This hearing took place on 14 October 2024 when, in addition to considering the court bundle, the court heard the oral evidence of Dr Hanrahan, Consultant in Neuro-Rehabilitation at the RHN and Professor Wade, Consultant in Neurological Rehabilitation and the oral submissions of the parties.

8. Judgment was reserved to enable the parties to consider what, if any, guidance should be given in cases such as this. That issue is considered in more detail below.

Relevant background

9. In late 2017 XR, then aged 55 years, suffered a cardiac arrest secondary to a myocardial infarction. XR received cardiopulmonary resuscitation from a bystander for about 10 minutes. He arrived at the Acute Hospital Emergency Department where a return of spontaneous circulation was achieved after a downtime of between 40 – 60 minutes.

10. XR remained being treated in acute hospitals until May 2018, when he was transferred to the RHN. Whilst in the acute hospital he was an inpatient in the Intensive Care Unit (ICU) until February 2018. During that time XR was started on epileptic medication for status epilepticus and in January 2018 had a tracheostomy inserted. The investigations carried out included:

    (1) An EEG which was reported to show appearances in keeping with generalised status epilepticus;

    (2) A CT scan which showed appearances suggestive of acute respiratory distress syndrome; and

    (3) A CT brain scan which showed appearances in keeping with hypoxic-ischaemic encephalopathy.

11. Following XR's discharge from the ICU in February 2018 an MRI brain scan reported findings of significant hypoxic ischaemic brain injury which Dr Hanrahan considered demonstrated evidence of a severe and worsening brain injury. EEGs in April 2018 reported features suggestive of widespread cortical dysfunction with no evidence of epileptic activity.

12. In early March 2018 XR's tracheostomy was removed following which he was able to breathe unaided, and a PEG tube was inserted shortly afterwards.

13. In May 2018 XR was assessed to be in a minimally conscious state (MCS). He had hypersensitivity to light touch, his pupils were reactive, he closed his eyes to visual threat, he had conjugate eye movements and he grimaced to pain appropriately. XR has significant contractures and high tone but there was spontaneous movement of his left shoulder and hip. Although XR had no verbal communication it was noted he would intermittently track people with some minimal facial expressions and he appeared to enjoy listening to music on TV with headphones on.

14. Following his transfer to the RHN in May 2018 he was initially admitted to the Brain Injury Service (BIS) before being transferred to the RHN's specialist nursing home in August 2018 where he remains.

15. XR continued to have annual reviews of his level of awareness in line with the Royal College of Physicians *Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines (2020)* (the 2020 RCP PDOC Guidelines). Over his stay in the RHN XR's level of consciousness has been assessed in accordance with the 2020 RCP PDOC Guidelines using the structured assessments as follows:

(1) the Wessex Head Injury Matrix (WHIM) on more than 45 occasions;

(2) the Coma Recovery Scale-Revised (CSR-R) on 5 occasions;

(3) the Sensory Modality Assessment and rehabilitation Technique (SMART) on 10 occasions; and

(4) The Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC) on 4 occasions.

16. In November 2023 Dr D, Consultant in Neuro-rehabilitation medicine at RHN, completed a PDOC checklist in which it was recorded that on initial assessments in 2018 XR was considered to be in a MCS but he had been consistently in the VS since 2019.

17. In August 2024 Dr Hanrahan, Consultant in Neuro-rehabilitation at the RHN, undertook a WHIM and CRS-R assessment, the results of which Dr Hanrahan considered confirmed XR is in a permanent VS.

18. XR is eligible for NHS Continuing Healthcare. His nursing placement at the RHN has been commissioned by the ICB since August 2018, although the RHN has responsibility for XR's day to day care.

19. XR's GP assessed XR's capacity in March 2024 and concluded that due the severity of XR's brain injury and PDOC, XR is unable to understand, retain, use and weigh, or communicate any relevant information required to make a decision regarding CANH and there is no prospect of recovery.

20. XR is able to breathe independently but has no reliable means of communication and has no awareness of himself or his surroundings. He receives CANH and medications through a PEG tube. He has severe physical impairments with no functional use of his lower or upper limbs, severe truncal weakness, global spasticity and frequent extensor spasms. He is also doubly incontinent and is dependent on two carers for all his personal care.

21. If XR remains in receipt of good nursing care his GP assesses his life expectancy could be up to 10 years. Dr Hanrahan assesses it at 6 – 8 years and Professor Wade considers his actuarial life expectancy to be about 5 years but considers

he may live for up to 10 – 20 years with good nursing care. If his CANH treatment was discontinued XR is expected to live for between 7 – 21 days/

Medical evidence

22. In her two statements Dr A, XR's GP, sets out that she has been one of XR's lead clinicians since he has been at the RHN. Having detailed the background she sets out her reasons for the decision that continuation of CANH was not in XR's best interests, however she acknowledges that when the multi-disciplinary team (MDT) had recently met to consider this they have considered the decision to be finely balanced as *'…the outcome and balance of the decision has shifted. Evidence from the various nursing staff is also variable, depending on his daily condition. In addition, given we do not know what [XR's] own views on this decision are (despite substantial efforts by us to identify persons with an interest in [XR's] welfare who we could consult), we do not feel confident in making a long term decisions and would appreciate some clarity from the Court of Protection as this is an unusual case.'*

23. Dr A sets out in her statement information about XR's past which appears to be taken from XR's historic GP records to help inform their decision about his best interests. The RHN was able to contact the person who visited XR in 2018 but he confirmed apart from that visit he had not seen XR since he was 2 – 3 years old. In May 2023 an IMCA was appointed who visited XR, spoke to hospital staff and with Dr A and provided a report dated 24 July 2023. There is no indication that the IMCA attempted to contact or seek records from any other NHS or local authority bodies and in reality provided no significant additional information.

24. In the later statement Dr A set out a summary of day to day life for XR. This included having medication administered through his PEG tube four times a day, regular daily observations (including blood, pulse, respiratory rate and oxygen saturations) and being checked by a nurse every one to two hours using a standardised protocol. XR has full personal care each morning (this includes washing his skin and cleaning of his PEG site with a full body shower 2 – 3 times a week), incontinence pads changed a number of times a day and oral suction if his secretions build up. XR is turned every 3 – 4 hours and hoisted out of his bed into his chair each day for four hours and then hoisted back to his bed. XR sometimes attends the sensory room.

25. In accordance with the 2020 RCP PDOC Guidelines a second opinion was sought by the ICB from Professor Wade, Consultant in Neurological Rehabilitation. He visited XR in April 2024 and in his detailed report he reviewed the history, analysed the factors to consider and summarised his conclusions as follows:

'After considering his situation (he is unaware and likely [in para 6.36 of his report he refers to this as a 'significant chance'] to be experiencing at least some pain and distress), his prognosis (no improvement and probably decline), and what was important to him from my own deductions using the evidence available, I concluded it was no longer in his best interests to continue gastrostomy feeding and hydration…I concluded that this was not a finely balanced decision. The circumstances are challenging, but the decision is relatively straightforward…'

26. In his report he considers that although there were some unusual features of XR's situation, for example, the absence of any family or friends to give information about the person or to act as his advocate and that it was reported XR had attitudes that are either illegal or contrary to widespread norms. In Professor Wade's view it was the circumstances surrounding the decision that made it challenging, but not so after proper analysis.

27. As regards any change for XR going forward Professor Wade said in oral evidence that there would be a *'general decline'* which would encompass such matters as weight loss and skin problems. He considered XR's treatment and care over time is likely to become more difficult and burdensome for XR.

28. Professor Wade makes the distinction between a response and awareness, regarding a grimace as a response. He considers XR's awareness of his environment is *'minimal and not detectable by me or anyone else'.* In relation to pain he considers if it is suffered it is *'in the moment',* XR would have no memory of it preceding it or ability to predict it is going to occur but he acknowledged the difficulties in this analysis and was not suggesting that XR could experience pleasure.

29. In his statement Dr Hanrahan outlined the background and confirmed that little is known about XR's social history, and he has had no visitors since August 2018.

30. He detailed the PDOC assessments undertaken since XR has been resident in the RHN and confirms XR has *'consistently been at the lower end of the consciousness spectrum; originally he was felt to be in an MCS- but since 2019, he has been assessed as being in a VS. It has been almost 7 years since the*

cardiac arrest which led to [XR's] brain injury. There has been no substantive change in his presentation since his admission to the RHN.'

31. Dr Hanrahan undertook his own PDOC assessments in August 2024 (WHIM and CRS-R) which he concluded were *'in keeping with the findings of [XR's] previous assessments.'* He agrees with Dr D's assessment in November 2023 that XR was in a permanent VS. A VS is defined as '*a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours. It is characterised by the absence of behavioural evidence for self or environmental awareness…There has therefore been no evidence of a sequential trajectory of behaviours along a hierarchy, as seen by both formal and informal observations, by specialist teams over many years. If this has been present, it would have indicated a change in [XR's] level of consciousness.'* As he notes the 2020 RCP PDOC Guidelines emphasises the absence of any awareness in this state.

32. In his written and oral evidence Dr Hanrahan addressed what had been described in the clinical observations of XR's facial expressions, for example a 'grimace', 'smirk' or his 'sleeping face'. He acknowledged the language used can be very subjective and influenced by the professional's perception of the underlying stimulus to the behaviour. He considers it is likely that there are a number of possible explanations for XR's facial expression in the broadest terms but it needs to be remembered that XR is in a VS and none of the behaviours represent any scientific conclusions on his consciousness, awareness, or experience. They would be explained, for example, by the shape

of XR's face, the influence of the particular stimulus or muscle atrophy. In his view '*It is almost impossible to determine what the expression itself denotes in isolation.'*

33. Dr Hanrahan recognises that the extent to which patients in a VS may possibly have a conscious experience of pleasure and pain is a *'complex area'*. He notes that Professor Wade considers the possibility that XR experiences the sensation of pain and, slightly less likely, an emotional state of distress or fear for much of the time. Dr Hanrahan does not consider that it automatically follows that the burden of uncomfortable treatments or interventions are actually experienced in a PDOC; as he observed just because someone might experience pain it does not mean that they do.

34. In his statement Dr Hanrahan confirms his view that XR's diagnosis and prognosis is *'secure, permanent, and irreversible'*. He acknowledges there is only limited information regarding XR's background and his previous wishes, feelings, values and beliefs but considers when reaching the best interests decision he did not consider the position to be 'finely balanced' although acknowledged Dr A as the decision maker did

35. In his view *'It is highly unlikely that [XR] has any awareness sufficient to support the clinical possibility that he has <u>any</u> conscious experiences that are painful or pleasurable. The responses seen are all reflexive and patterned, though they may have lessened in nature and intensity more recently. None of these behaviours are convincingly high or consistently present to indicate any residual consciousness. Undoubtedly these behaviours have resulted from his greater burden of daily nursing care, with increasing doses of medication*

needed to maintain an acceptable level of personal hygiene and manage his reflex distress behaviours during moving and handling'.

36. Dr Hanrahan acknowledges he has co-authored a draft article with Professor Wade where they reflect that if a person demonstrates any behaviours that suggest pain or distress, whether experienced or not, they should be treated appropriately. They then put forward different hypotheses as to what these pain behaviours may mean in a PDOC like the VS. Dr Hanrahan makes clear this draft article has not been peer reviewed.

37. Focussing on XR's position Dr Hanrahan concludes *'in a pragmatic clinical way'* is that XR does not have this conscious experience as he is in a VS although he acknowledges others consider XR may '*at some very low and unprovable and unknowable level experience any stimulus as a negative painful sensation. There is no consensus on what this experience is. This possibility, if anything, further emphasises the need for adequate anticipation and relief of this distress. It must be noted that the remote possibility of this distress being experienced is conclusively outweighed by the patently obvious need to respond humanely and compassionately to distress.'* He continues '*This obviates the need for as laboured distinction as to whether someone needs to experience pain…to be treated for it, and that it is permissible to treat visible distress even when it is simply not possible to experience it.'*

Timetable of decisions in this case

38. ICBs are statutory bodies responsible for planning health services for their local population and have the duty to arrange for the provision of such services or facilities as they consider appropriate in accordance with their statutory duty.

The ICBs do not provide primary or acute medical care. Such care is commissioned via NHS or private care providers. In XR's case the ICB commissions his care from the RHN.

39. The relevant Clinical Lead at the ICB states in the written evidence *'It is for the commissioned provider, which is regulated by the CQC, to prepare an appropriate care plan which meets the needs of the patient or service user in question, share a copy of this with the ICB and keep the ICB informed of any change in needs or the package of care being provided….The ICB relies on the expertise of those from whom care is commissioned as it does not itself have the function to provide such care. 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).*

40. The ICB statement continues that such reviews took place regarding XR's needs in October 2019, August 2022, May 2023 and April 2024. The gap between 2020 – 2021 was due to the pandemic. It is open to providers to contact the ICB in between such reviews, if required.

41. In relation to XR the ICB was first informed that there was uncertainty from the clinical team in relation to whether continued CANH was in XR's best interests in November 2023. The RHN continued to seek to ascertain XR's wishes and feelings until February 2024. The best interest decision was made by XR's clinical team at the RHN that it was not in XR's best interests for CANH to continue on 22 March 2024. By that stage an IMCA had been appointed but had been able to gain little, if any, additional relevant information.

42. The best interests decision was considered to be finely balanced largely due to the limited information the clinical team had regarding XR's wishes and feelings, hence the ICB's application to the Court of Protection on 8 April 2024.

43. Following this application being issued the court made directions for the Official Solicitor to attempt to ascertain XR's wishes and feelings. The Official Solicitor informed the court and the parties of the steps taken at the end of May 2024, which had not revealed any additional information, and provided an update in July and October 2024.

44. With the assistance of third party disclosure orders the Official Solicitor was able to gain records from agencies which Dr A the RHN and the IMCA had not, such as mental health services and the local authority. In addition the Official Solicitor was able to obtain information from Mr U and Mr R, which was not previously available.

45. In the end this additional information has not proved decisive or informative as to XR's wishes, feelings, beliefs and values, but it could have been.

46. In effect, the Official Solicitor had reviewed XR's previous GP and other records. From those records the Official Solicitor has been able to glean the following information: XR consulted his GP reasonably frequently, on about 34 occasions between 2000 – 2017; some of those visits to the GP were for assistance with making sickness benefit claims; there is reference to XR's inconsistent engagement with mental health services; XR appears to have felt alienated from society due to the views he held, although there are some references to XR's friends; there had been long periods when XR was out of

work and had been homeless with the need to seek local authority accommodation.

Legal framework

47. The parties produced a helpful agreed summary of the relevant legal principles.

48. Where a person lacks capacity to decide for themselves, any decision must be made in their best interests (s1(5) MCA 2005).

49. In the context of decisions as to whether to withdraw life-sustaining treatment, the Supreme Court in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 (at §22) identified the ambit of the court's inquiry as follows:

"... 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." [emphasis added]

50. CANH is recognised as a medical treatment amenable to such a determination (per Lady Black, with whom the other members of the court agreed, in *An NHS Trust v Y* [2018] UKSC 46).

51. The starting point for any best interest analysis is a strong presumption that it is in a person's best interests to stay alive, considering their rights under Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for private and family life) of the European Convention on Human Rights ("ECHR").

52. The strong presumption of maintaining life, however, can be displaced by evidence that it would be contrary to a person's best interests to continue receiving life-sustaining treatment. Having enunciated this point, Lady Hale in *Aintree* continued that:

"36. *The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and every case, is different and must be decided on its own facts. As Hedley J wisely put it at first instance in Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as Bland, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time."*

53. Where a decision relates to life-sustaining treatment, the person making the decision must not *"be motivated by a desire to bring about his [P's] death"* (s4(5) MCA 2005).

54. When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and

feelings, to the beliefs and values that would be likely to influence their decision if they had capacity, and to the other factors that they would be likely to consider if they were able to do so (s4(6) MCA 2005).

55. Account must be taken of the views of anyone engaged in caring for the person or interested in their welfare (s4(7) MCA 2005).

56. The MCA 2005 Code of Practice ("the Code"), issued pursuant to s.42 MCA 2005, provides guidance in respect of best interests decision-making around life-sustaining treatment. This includes that:

"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."

"5.38. In setting out the requirements for working out a person's 'best interests', section 4 of the MCA 2005 puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests…"

"5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)."

57. The holistic nature of the best interests analysis was expressed by Lady Hale in *Aintree* as follows [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".*

58. At [45] she added:

"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. .... 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".

59. A number of cases have sought to provide a helpful non-exhaustive list of issues requiring determination in an application of this kind, for example Cobb J in *PL (by her litigation friend, SL) v Sutton CCG & Anor* [2017] EWCOP 22 at [9].

Submissions

60. The ICB submit in the light of the clear evidence as to diagnosis, prognosis and capacity the focus is on what is in XR's best interests. They submit the important presumption of preserving life is outweighed by the burdens of the extent of XR's brain injury, the many and difficult daily interventions required to care for him, the trajectory that his condition is likely to decline, and the futility of the treatment in the sense that it provides no effect on his underlying condition. Ms Watson KC cautions against speculation about XR's underlying wishes and feelings; unusually in this case that information is not known despite extensive efforts to secure information about that.

61. Ms Scott on behalf of the RHN agrees with the submissions on behalf of the ICB. The court should not seek to draw inferences about XR's wishes and feelings due to the paucity of information the court has. As regards pain Ms Scott submits the court can factor into the balancing exercise that there is a risk of XR experiencing pain. However, she submits, the best interest decision is not dependant on that aspect due to the other evidence of the significant burdens for XR.

62. Mr Horne KC, on behalf of the Official Solicitor, submits the evidence demonstrates the significant burdens for XR of the continuation of treatment, irrespective of the issue of pain. The high level of repeated interventions required need to be considered in the context of a deteriorating clinical picture. On behalf of the Official Solicitor he recognises the presumption of the sanctity of life but, as he submits, the reality is the person XR was has long gone. He submits the important component of the balancing exercise of what XR would

have thought is not available here. There is evidence of a picture of XR's life but it would be unsafe to draw any conclusions as to his wishes and feelings from that limited information as it carries with it the risks of speculation. The dangers of that were illustrated by the fact that some of the inferences made about XR's background have been put into doubt through the limited additional information the Official Solicitor has been able to obtain about XR.

Discussion and decision

63. There is unanimity in the medical evidence that XR is in a permanent VS and that condition is not going to change. There is no issue that XR lacks capacity to make the decision as to whether CANH should be continued or not. As a result the focus must be on what would be in XR's best interests.

64. The evidence details the significant daily interventions required to care for XR on a day to day basis in order to maintain his current stability of care. I agree with both Dr Hanrahan and Professor Wade that the trajectory for XR is he will decline. This is due to the inherent risks caused by the high level of care he requires and the seriousness of his injuries, for example he is at risk of skin infections or secondary complications like a chest infection, and the additional burdens of further interventions required to manage that decline.

65. Dr Hanrahan was clear in his evidence, which I accept, that the day to day interventions for XR are burdens without a benefit as there is no prospect of any recovery and, as a consequence, he considered the interventions are futile for XR. He accepted as a theoretical possibility that XR could experience pain but did not consider it likely in XR's case as due to the nature and extent of his injuries XR would not have an awareness of it. Professor Wade raises the

question of whether XR experiences pain *'in the moment'* but I agree with Dr Hanrahan that whilst he and Professor Wade may emphasise different aspects of the possibility of whether XR shows a response to pain they both clearly end up at the same conclusion regarding what is in XR's best interests.

66. I agree with the submissions of all parties that in the particular circumstances of this case the court should not make any inferences on the limited information it has about XR regarding his wishes and feelings. To do so would bring with it a high risk of speculation. The reality is that despite the extensive efforts made by the RHN and the Official Solicitor little reliable information is known as to what XR's wishes and feelings would be regarding the decision the court is faced with now. I am satisfied no further enquiries can or should be made and this is one of those relatively rare cases where it is not possible to ascertain or assess XR's wishes, feelings, beliefs and values under s4(2) and (6) MCA or those of his family or friends.

67. Whilst I recognise and carefully weigh in the balance the strong presumption in favour of preserving life I am satisfied when considering the evidence as a whole that it is not in XR's best interests to continue to be in receipt of CANH. This is because the benefits of such treatment continuing are significantly outweighed by the considerable burdens for XR caused by the daily care interventions, of which there is detailed evidence, that are required to continue in the context where there is no prospect of any change in XR's diagnosis or prognosis. I accept the evidence of both Dr Hanrahan and Professor Wade of a trajectory of decline in XR's position where the burdens of such treatments and interventions are likely to increase. For the reasons set out above XR's wishes

and feelings are unknown and, as a consequence, cannot be factored in the court's consideration of what is in his best interests. The issue between Dr Hanrahan and Professor Wade as to whether XR can experience pain is considered in the context of there being a risk of the possibility that XR may experience pain but it can be no higher than that and in the light of the other considerations that factor, in the circumstances of this case, does not have a material bearing on the balancing exercise undertaken by the court in reaching a decision as to what is in XR's best interests.

68. I am satisfied this case was rightly the subject of an application to the Court of Protection. The decision maker, Dr A, considered the position to be finely balanced. Even though others took a different view that clinical decision and judgment should be respected. It is important that having properly considered the relevant Guidelines/Guidance clinicians should not feel under pressure either way regarding decisions that they have reached. Having said that, it remained unclear what system, if any, was in place for seeking disclosure of XR's records, who was undertaking that, and what role the IMCA played. In this case it is right to record that the Official Solicitor was able to gain more information about XR through the third party disclosure orders made once these proceedings were commenced. In the end it made no difference to the information that was available, although it could easily have done, and if the application had not been made would have risked relevant information not being available in reaching a best interest decision.

Guidance

69. In their written submissions prior to this hearing each party invited the court to provide judicial guidance in cases such as this where those charged with making a best interest decision considered it to be finely balanced due to the lack of information about a patient's likely wishes, feelings, beliefs and values.

70. In *An NHS Trust and others v Y* [2019] the Supreme Court held that if the provisions of the MCA are followed and the relevant professional guidance observed, and there is agreement upon what is in the best interests of the patient, the patient may be lawfully treated in accordance with that agreement without application to the court. At [125] Lady Black concluded

'*If at the end of the medical process, it is apparent that the way forward is finely balanced, or there is a difference of medical opinion or a lack of agreement to a prolonged course of action from those with an interest in the patient's welfare, a court application can and should be made. As the decisions of the ECtHR underline, this possibility of approaching a court in the event of doubts as to the best interests of the patient is an essential part of human rights…'.*

71. In *Y* the Supreme Court did not provide an exhaustive list of such cases but did observe at [126]

'…I would emphasise that, although application to court is not necessary in every case, there will undoubtedly be cases in which an application will be required (or desirable) because of particular circumstances that appertain, and there should be no reticence about involving the court in such cases.'

72. In the Guidance issued by Hayden J following *Y* in *Applications Relating to Medical Treatment: Guidance Authorised by the Honourable Mr Justice*

Hayden, The Vice President of the Court of Protection [2020] EWCOP 2 (The Vice President's Guidance) it is stated at [8]

'If at the conclusion of the medical decision-making process, there remain concerns that the way forward in any case is:…(d) there is a potential conflict of interest on the part of those involved in the decision-making process (not an exhaustive list) then it is highly probable that an application to the Court of Protection is appropriate. In such an event consideration must always be give as to whether an application to the Court of Protection is required.'

The Vice President's Guidance continues at [9]

'*Where any of the matters at paragraph 8 above arise and the decisions relates to the provision of life-sustaining treatment an application to the Court of Protection* ***must*** *be made. This is to be regarded as an inalienable facet of the individual's rights, guaranteed by the European Convention of Human Rights ('ECHR'). For the avoidance of any doubt, this specifically includes the withdrawal or withholding of clinically assisted nutrition and hydration'.*

73. The 2020 RCP PDOC Guidelines consider when an application to court is required stating at 4.8.2 under the category of 'Finely balanced' decisions for which court determination is required:

'Other examples may be where the patient has never been able to express their wishes and feelings or where there is absolutely no information about their life before brain injury, despite the involvement of an IMCA. In reality,

however, this group will be small as it is very rare not to be able to get some information about the individual's life story to guide the decision.'

74. S42(2) and (5) MCA requires decision makers to have regard to the Code of Practice. At 5.39, 5.41 and 5.51 the Code emphasises the importance of *'all reasonable efforts must be made'* and, if required, decision makers must be able to explain why they did not speak to a particular person in seeking out as much information as possible to inform the consideration under s4(6) MCA. This emphasises that consideration is not restricted to previously expressed views limited to the continuation of CANH. It includes the beliefs and values that would be likely to influence their decision if they had capacity and the other factors that they would be likely to consider if they were able to as derived from the broader canvas of their life.

75. In circumstances involving the provision of serious medical treatment where an NHS body is satisfied there is no person whom it would be appropriate to consult in determining what would be in the patient's best interests s37 MCA requires the appointment of an IMCA. Their role and function is set out in paragraph 6 of The Mental Capacity Act 2005 (Independent Mental Capacity Advocates)(General) Regulations 2006. An IMCA is able to access information in the patient's health, care or social services records (s35(6) MCA). The IMCA report in this case does not provide any information as to what steps, if any, were taken by the IMCA to access information to in XR's records.

76. In her written submissions at the start of this hearing the Official Solicitor submitted *'Absent rigorous efforts to obtain information about P for the*

purposes of s4(6) MCA, there is inevitably a danger that the focus will fall not on what treatment choice they would have made, but on other aspects of the best interests test such as the medical prognosis and quality of life.' At that stage the Official Solicitor submitted that in a PDOC case in which it is not possible to ascertain P's wishes, feelings, beliefs and values because there are no family members or persons with an interest in P's welfare to consult and even with the proportionate independent second opinion that the 2020 RCP PDOC Guidelines, require the *'treating team who proposed the withdrawal of CANH are effectively judges in their own cause'* and it is in such a patient's best interests for the issue of continuation of CANH to be determined by the court. The Official Solicitor contended that *'Quite apart from rigorous judicial consideration of their best interests in relation to the treatment decision, an application would result in the appointment of the Official Solicitor as their litigation friend, her independent analysis of whether further investigations should be undertaken, and further information sought, with the compulsion of a TPDO [third party disclosure order] where appropriate.'*

77. Directions were made at the end of the hearing for the parties to liaise to produce an agreed note regarding any judicial guidance that was being sought. Since that direction the position of the parties has changed.

78. On the application of the RHN permission was given for a draft of any proposed guidance to be sent to Professors Turner-Stokes and Wade in their capacity as the Chair and co-chair of the 2020 RCP PDOC Guidelines. In a letter dated 27 October 2024 they informed the court and the parties that the RCP

is already in dialogue with the British Medical Association (BMA) and the General Medical Council (GMC) and is convening an appropriate multi-agency sub-group to develop updated supplementary guidance to address issues raised in recent cases. The letter cautions against issuing any guidance based on a single case with the views limited to those involved in the case.

79. The RHN supports that position and no longer invites the court to formulate judicial guidance but does invite the court to *'explain its views as to whether this case should have been brought before the Court and to explain why'.*

80. The Official Solicitor largely maintains her position about the need for judicial guidance and proposes the court should identify the following as a category of case which must be brought to court:

> *Cases where P is clinically stable in which there is a consensus within the treating clinical team that it is in P's best interests not to continue longstanding treatment which, if discontinued, will result in P's death, but*
>
> - *there are no family members, persons interested in P's welfare, or persons engaged in caring for P (other than those acting in a professional capacity or for remuneration) who are available to consult;*
>
> *and*
>
> - *either the treating clinical team or any appointed IMCA have concerns that they cannot, from the information available to them, reasonably ascertain P's past and present wishes and feelings about that decision, the beliefs and values that would be likely to influence P's decision if P had capacity, and the other factors that P would be likely to consider if P was able to do so.*

81. The Official Solicitor does not support the suggestion to await the outcome of the RCP process due to the lack of any given timescale as to when that may be

available and questions whether the existing 2020 RCP PDOC Guidelines provided sufficient safeguards in this case. In light of this court's decision in *NHS North West London Integrated Care Board v AB & Ors* [2024] EWCOP 62 re-emphasising the need for timely best interests decisions and applications to the Court, the Official Solicitor considers that there may be a renewed focus nationally on the best interests of patients in PDOC in the months ahead. Until the recent letter from Professor Turner-Stokes and Professor Wade the RHN had advocated judicial for guidance to give greater clarity.

82. The Official Solicitor submits that context needs to be considered. The UK Parliament Postnote No 674 July 2022 records there are 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 cared for in other settings. In his oral evidence, Professor Wade recognised there was a group of patients in PDOC where the clinicians carry on providing CANH by default because there are no friends or family to consult. Within that group, the Official Solicitor submits, there may be patients who are currently receiving life-sustaining treatment the continuation of which may not be in their best interests. In the Official Solicitor's view even in a specialist setting such as the RHN XR was the subject of annual reviews from 2019 when he was assessed as being in a VS yet no application was made to the court until five years later in April 2024.

83. The Official Solicitor submits whilst the ICB rightly brought this application, when it was made the second opinion in accordance with the 2020 RCP PDOC Guidelines had not been obtained and Professor Wade's firm conclusion was

based, in part, on inferences he made regarding XR's wishes and feelings and beliefs and values which the Official Solicitors submitted was incorrect and not soundly based.

84. The Official Solicitor submits judicial guidance that requires (as a matter of practice not as a rule of law) cases such as XR's to be brought to court will facilitate

> *a) rigorous judicial consideration of P's best interests in relation to the treatment decision;*
>
> *b) the appointment of the Official Solicitor as their litigation friend, her independent analysis of whether further investigations should be undertaken and further information sought, with the compulsion of a TPDO where appropriate; and importantly*
>
> *c) a reduction in the pool of patients who are unlawfully receiving continued longstanding life-sustaining treatment by default because of an absence of family or friends to consult.*

85. Any judicial guidance given at this stage can, the Official Solicitor submits, be revised, if appropriate, in light of any supplementary national RCP PDOC Guidelines published in the future.

86. Whilst the RHN's primary position was that the court should not issue any guidance, in their written submissions they made observations on the proposed draft submitted by the Official Solicitor.

87. The ICB largely supports the submissions of the Official Solicitor.

88. I have carefully considered the detailed and measured submissions on behalf of the Official Solicitor and recognise the very real concerns she has in this case, as she did within a different factual context in *GU* and *AB*. The court shares that concern noting, as the Official Solicitor submits, that even in a specialist facility such as the RHN XR remained drifting in a vacuum of ineffective best interest decision making for a number of years. To that extent the observations in *AB* for a structure that provides for timely best interest decisions being made apply as much in this case in the same way as it did in *AB*.

89. Not without some hesitation, I am, at this stage, going to decline the invitation for judicial guidance as I recognise the robust process referred to by Professor Turner-Stokes and Professor Wade has been started. The message from this judgment is for that to take place without undue delay, and for a timetable and framework for that review process to be published as a matter of urgency so that any revised Guidelines can be in place sooner rather than later and there is transparency about the timeframe for when that will take place.

90. Pending that, this case and *AB* provide an important timely reminder to any facility responsible for a patient in PDOC to carefully and proactively consider the relevant Guidelines/Guidance (both the 2020 RCP PDOC Guidelines and the Vice President's Guidance), to ensure there is a rigorous process for best interest decisions in operation by those responsible for that patient's care which is in accordance with the relevant Guidelines/Guidance, and that any decisions for applications to the Court of Protection are, if required, promptly brought before the Court without undue delay or drift.

91. It is also important in the relatively unusual cases such as this, where the wishes and feelings of the patient are not readily available, to have clarity about who is responsible for making enquiries and seeking records about that person to avoid delay and ensure there is consistency in approach to obtaining this important information. In such circumstances a relevant part of the decision whether to make an application to the Court of Protection could involve the power of the court to make third party orders for disclosure and the rigorous support the Official Solicitor can provide to ensure that is done.

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.' and

[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.