Neutral Citation Number: [2023] EWCOP 32

Case No: 14094683

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 21 July 2023

Before:

MR JUSTICE POOLE

- -

Re IN (Withdrawal of CANH)

Between:

HILLINGDON HOSPITALS NHS FOUNDATION TRUST	**Applicant**
- and –	
(1) IN (By his Litigation Friend, The Official Solicitor) **(2) AN** **(3) MN**	**Respondents**

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Rhys Hadden (instructed by Clyde & Co LLP) for **the Applicant**
Emma Sutton KC (instructed by the Official Solicitor) for **the First Respondent**
AN and **MN** in person

Hearing dates: 21 July 2023

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JUDGMENT

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Mr Justice Poole:

Introduction

1. The person who is subject of these proceedings is IN, a 55 year old man originally from Romania who has lived in England for many years. He was married but separated several years ago and lost contact with his ex-wife. He has one daughter, AN who currently lives in Romania and who is the Second Respondent. The Third Respondent is IN's brother, MN, who lives in England. IN lived on his own in social housing in Greater London. He previously worked as a delivery driver. He is a big man – tall and heavy. He is described as a family man with a strong Catholic faith and "a fighter". On 29 December 2022 IN was driving when he suffered a severe pontine haemorrhagic stroke leading to a cardiac arrest and hypoxic brain injury. He has been in a coma for over six months. Brain scans show that his brain has atrophied globally. He is currently cared for at Hillingdon Hospital where he is receiving care including Clinically Assisted Nutrition and Hydration (CANH).

2. The Applicant Trust, responsible for Hillingdon Hospital, considers that the IN's coma is irreversible and there is no prospect of recovery such that further treatment is futile and will bring him no benefit. It maintains that the burden of continuing CANH cannot be justified as being in IN's best interests and invites the Court to make declarations and orders that it would be lawful to withdraw CANH and for IN to receive palliative care only. It is likely that within a week or so of withdrawing CANH, IN will die.

3. IN's condition is one of a Prolonged Disorder of Consciousness (PDOC), a term which can encompass minimally conscious states, vegetative states, and coma. The medical evidence, discussed later in this judgment, is that IN has a lower awareness status that a vegetative state and is in a permanent coma.

4. In *An NHS Trust v Y* [2018] UKSC 46, Lady Black, with whom the other members of the court agreed, made a number of observations that help decision-makers navigate the troubled waters of end of life decision making. First, in relation to CANH, Lady Black said at [116],

> "It is important to acknowledge that CANH is more readily perceived as basic care than, say, artificial ventilation or the administration of antibiotics, and withholding or withdrawing it can therefore cause some people a greater unease. However, it was decided as far back as the *Bland*[1] case that CANH is in fact to be seen as medical treatment."

Second, at [119] Lady Black advised against relying on the categorisation of a patient's condition to dictate best interest decisions.

[1] *Airedale NHS Trust v Bland* [1993] AC 789 concerned a man who had been left in a what was then referred to as a persistent vegetative state after being injured in the Hillsborough disaster.

> "In any event, I have difficulty in accepting that there are readily apparent and watertight categories of patient, with PDOC patients clearly differentiated from, say, patients with a degenerative neurological condition or critically ill patients, in such a way as to justify judicial involvement being required for the PDOC patients but not for the others. The dilemmas facing the medical team and those close to the patient may well be very similar in each of these cases. It would be a mistake to think, for example, that the intensive care doctor simply does whatever is necessary to stop the patient dying, no matter what the cost to the patient, any more than does the doctor looking after a PDOC patient or the stroke patient or the patient with Huntington's disease. In all of these cases, the medical team take their decisions as to treatment, whether it is CANH, or some other form of treatment such as artificial ventilation or cardio-pulmonary resuscitation or the administration of antibiotics, by determining what is in the patient's best interests. In so doing, the doctors will often have difficult diagnoses to make, reaching a prognosis may be challenging, and the evaluation of the patient's best interests may not be entirely straightforward. All these tasks may call for considerable professional skill and individual judgement."

Third, Lady Black noted the importance of professional guidance:

> "[124] The documentation supplied to us shows that the difficulty that there is in assessing the patient and in evaluating his or her best interests is well recognised. The process is the subject of proper professional guidance, covering vitally important matters such as the involvement in the decision-making process of a doctor with specialist knowledge of prolonged disorders of consciousness, and the obtaining of a second opinion from a senior independent clinician with no prior involvement in the patient's care. The second opinion, as contemplated in the guidance … is, in my view, a crucial part of the scrutiny that is essential for decisions of this sort, and the guidance sets parameters which should ensure that it is an effective check, in that the clinician who provides the second opinion must (so far as reasonably practical in the circumstances of the case) be external to the organisation caring for the patient, and is expected to carry out his or her own examination of the patient, consider and evaluate the medical records, review information about the patient's best interests, and make his or her own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient. Thus the interests of patients and their families are safeguarded, as far as possible, against errors in diagnosis and evaluation, premature decisions, and local variations in practice."

End of life decisions including the withdrawal of CANH may not require the involvement of the Court "if the provisions of the Mental Capacity Act 2005 (MCA 2005) are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient" [126] but,

> "[125] 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 proposed 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 the protection of human rights. The assessments, evaluations and opinions assembled as part of the medical process will then form the core of the material available to the judge, together with such further expert and other evidence as may need to be placed before the court at that stage."

5. IN's family - his daughter AN and brother MN – oppose the Trust's application. They do not dispute the medical analysis but contend that IN would have wanted CANH to continue so that he could be kept alive for as long as possible. He was a "fighter" whose Christian faith would have led him to believe that God might perform a miracle to bring him back to consciousness and a fuller life.

The Law

6. IN clearly lacks capacity to conduct this litigation and to make decisions about his treatment. No party dissents from that and the evidence of the lack of capacity to make any decisions is incontrovertible. The presumption of capacity is displaced and therefore decisions about treatment have to be made on IN's behalf. By MCA 2005 s1(5), "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests." MCA 2005 s4 provides,

> <u>Best interests</u>
>
> (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).

7. IN has not made an advance decision and has not appointed an attorney. By ss 16 and 17 MCA 2005 the court may, by making an order, make the decision or decisions on P's behalf in relation to a matter or matters concerning P's personal welfare, including giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P. The exercise of such powers is subject to the principles set out in ss 1 and 4 of MCA 2005, and therefore to the principles governing the determination of a person's best interests.

8. The Mental Capacity Act 2005 Code of Practice ("the Code"), issued under MCA 2005 s42 includes a section within Chapter 5 entitled "How should someone's best interests be worked out when making decisions about life-sustaining treatment?" It includes the following:

> "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 … 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." "5.36 As mentioned in para 5.33 above, where there is any doubt about the patient's best interests, an application should be made to the Court of Protection for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests."

9. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 at [22] Baroness Hale said,

> "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."

And at [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. The burden of establishing that the discontinuance of life-sustaining treatment is in a person's best interests lies with he who asserts that it should be withdrawn, here the Applicant Trust: *R(Burke) v GMC (OS Intervening)* [2005] QB 424. The civil standard of proof on the balance of probabilities applies, including in relation to any findings of fact.

The Evidence

11. Dr A, consultant in rehabilitation medicine is the consultant responsible for the care of IN. He gave written and oral evidence to the Court in which he detailed IN's injuries, condition, and prognosis. IN's stroke caused two insults to his central nervous system on 29 December 2022: a pontine haemorrhage followed by a hypoxic brain injury caused by an out of hospital pulseless electrical activity arrest with a down time of 15 minutes. IN was transferred from St Thomas' Hospital Intensive Treatment Unit to Hillingdon Hospital on 2 March 2023. IN has remained in a coma since his stroke with no stimulus induced eye-opening, no response to any stimuli, and no voluntary

responses. Several brain scans and electrophysiological studies have ruled out any reversible pathology and scans performed in March 2023 showed global shrinkage of the brain when compared with scans performed in December 2022.

12. IN is self-ventilating with a tracheostomy tube with inflated cuff and is receiving CANH through a nasogastric tube. He has a catheter in situ and is totally dependent on nursing staff for all elements of his care. He has been treated with antibiotics after a raised temperature and positive blood culture. Since 15 May 2023 he has required oxygen to maintain oxygen saturation over 90%. IN has a history of ischaemic heart disease. During this admission there has been a gradual increase in generalised oedema due to poor cardiac reserve, for which he is administered IV Frusemide. IN is diabetic who had had a toe amputated before his stroke, and he is administered insulin before his morning and evening feeds.

13. Structured assessments using measures recommended by the Royal College of Physicians guidelines on PDOC have been performed to assess and record his level of awareness over time. Coma Recovery Scale- Revised assessments have been conducted with scores remaining at zero. Sixteen Wessex Head Injury Matrix assessments have been completed with the total number of behaviours observed being consistently zero. IN has presented with little to no indication of pain, despite some know painful conditions such as broken skin. He now has skin breakdown on his legs. He does not have a sleep-wake cycle. Nociception is a biological warning system that responds to actual or potential noxious stimuli: it may not involve consciousness but is a function of a specific sensory system. Application of the Nociception Coma Scale (NCS) shows scores falling within the "no nociception" category suggesting that IN cannot feel pain. IN has been seen to grimace when moved or when his tracheostomy is suctioned, but at other times there is no response. There is no consistent response to indicate that he is in pain or is suffering. All the assessments and observations are in keeping with IN being in a coma. The conclusion is that he does not have awareness of himself or the environment around him.

14. There have been a number of Best Interests meetings which have included family members. The view of Dr A and other specialists from various fields of expertise at the Hospital is that IN's prognosis is extremely poor. There is no sign of a positive trajectory in terms of awareness. It is highly unlikely that he will emerge into full consciousness. In early May 2023 there were occasional episodes of spontaneous eye opening meaning that Dr A thought that there might be a possibility that IN might progress to a level of vegetative state. However, Dr A said that IN has remained in a coma, with no established sleep-wake cycle, which is below the level of consciousness of a vegetative state and he told the court that the prospects of IN progressing even to a permanent vegetative state were now "almost non-existent". The Royal College of Physicians Guideline, Prolonged Disorders of Consciousness Following Sudden Onset Brain Injury, 2020, uses the following definition of vegetative state:

> '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.'

A patient in a coma has no established sleep-wake cycle. Usually a patient in a coma will recover, progress to a vegetative state, or die within a few weeks. It is unusual for a person to remain in a coma for as long as IN. The RCP Guideline recognises a permanent vegetative state (lasting over six months) but not a permanent state of coma as a specific categorisation of PDOC. Hence, Dr A and others have at times referred to a permanent vegetative state in an attempt to find a classification that reflects the chronicity of the PDOC in IN's case. However, IN's level of consciousness is below that of a vegetative state. He has been in a coma for over six months and there is no positive trajectory. The Clinical Support Group (CSG) at the Trust has met to discuss the treatment options for IN and concluded that there is no prospect of any recovery of any functions or improvement to a quality of life that IN would be likely to value, continued CANH would be futile as would treatment of infections and other life prolonging measures. The view of the CSG is that it is in IN's best interests to withdraw CANH and to commence palliative care.

15. Dr A has produced a step-by-step plan for withdrawal of CANH. IN's tracheostomy would remain in situ. Dr A says that IN would be expected to survive for one to three weeks after the first step of the plan was implemented. Palliative care would be given including morphine which would mitigate any possible distress or pain suffered by IN. If there were, wholly unexpectedly, any signs of increased awareness or improvement, then the team would step out of the plan and seek further opinion. The plan would start within 10 days of the court giving authorisation for it in IN's best interests in order to accommodate AN travelling to England to be with IN at the hospital. IN would be moved to a single bedroom when the plan was implemented. Dr A would remain involved throughout. Dr A said that he would expect IN to survive for between one to three weeks.

16. Removing the tracheostomy would hasten IN's death on the withdrawal of CANH but could cause distress to the family and to staff at the hospital because of the effect it would have on IN struggling to breathe.

17. Dr A has discussed IN's likely wishes and feelings and his beliefs and values with AN but she has said that she and her father had never discussed the sort of situation in which he now finds himself.

18. If CANH were to be continued, then the plan would be to insert a gastrostomy for feeding and to transfer IN to a nursing home that can look after residents with a tracheostomy. Optimistically that process might take a month, but may take longer because of the scarcity of beds in such nursing homes. Dr A said that he would expect IN to survive for between three and six months.

19. Tellingly, Dr A said that he has been a consultant at Hillingdon Hospital for 18 years and this is the first occasion on which he has sought authorisation to withdraw CANH. He said in his oral evidence,

> "I find it distressing and difficult but the science is irrefutable – not one patient of mine has remained in a coma for 7 months but remained medically stable to continue. That is why on this one occasion we approach the court for withdrawal of CANH. This is the harder option compared to the easier option of

> putting in a feeding tube and transferring the patient to a suitable nursing home, but I strongly believe it is the right one."

20. Both AN and MN gave powerful evidence to the Court. AN participated in the hearing by remote link from Romania. She had written an email to the Court dated 26 June 2023 in which she says that she is using her "last strengths in order to defend my father's life". He has "been through a lot of bad things in his life and he always won." She describes him as a "kind, happy, loving man and he would always make you laugh even in your darkest times, he is the type of father who will be your support even if he might be the one who needs that… My father and I have been always close and since my daughter was born they always shared a special connection." She said that her father "as a man of faith, he always said that life belongs to God and if we live, we live to the Lord, and if we die we die to the Lord and it will never be up to us on Earth to decide who deserves to live…" She expressed the view that the desire to save money lay behind the Trust's application. She informed the court that she would want to travel to the UK if the plan to withdrawal CANH were to be implemented but is unsure how long she would be able to remain here – she has family commitments in Romania. AN decided not to give oral evidence at the hearing.

21. MN gave oral evidence with the help of an interpreter. His evidence was heartfelt and moving. He said that on visiting his brother at the hospital at weekends and some evenings he has not met a doctor. This is unfortunate but is due to the fact that there is no doctor on the ward at those times – there are doctors in the hospital but they would only attend a ward if there was a specific clinical need. Dr A accepted that he ought to arrange a meeting with MN. MN told the Court that IN was a "jolly man" – a big man with a big heart. He worked as a delivery driver. Last year he underwent cardiac bypass surgery but came through it and returned to work within two to three months. IN grew up attending the Romanian Orthodox Church and continued to attend that church in England every Sunday. MN believes it to be in his brother's best interests to continue CANH – he asked why anyone would decide not to let him live the remaining three to six months he had left.

22. I have received expert evidence from Dr Hanrahan, Consultant in Neuro-rehabilitation at the Royal Hospital for Neurodisability in Putney. He is on the RCP Guideline Development group 2020 for PDOC. He was asked by the Applicant trust to provide a second opinion, something he has significant experience in doing. He has visited IN twice, on 3 June and 14 July 2023, and has spoken to AN and, separately to MN and his wife. His reports are thoughtful, sensitive, and show that he has taken great care in preparing and presenting his evidence. He agrees with the medical picture painted by Dr A. He himself conducted neurological observations and found no response to all standard stimuli including pain. Both corneal reflexes were absent. His respiration was described as "pathological cyclical breathing of central origin with brief (5-6 seconds) of apnoea and thereafter deeper breathing" which, according to Dr Hanrahan, has a "poor prognosis for recovery of consciousness". He told me that IN is now in a permanent coma. He says that IN's occasional eye opening "does not, in any way, herald or provide evidence of any awareness." IN is at significant risk of death within the next few weeks or months. Treatment with antibiotics is likely to have saved IN's life and Dr Hanrahan has questioned whether it is in IN's best interests to continue with a plan to give antibiotics in the event of future signs of infection. The

Trust has not changed its plan in that regard because AN was not involved in discussions about a plan not to administer antibiotic treatment. Dr Hanrahan has concluded after his first visit that IN is at,

> "the most severe end of the 'spectrum' of what is already a profound brain injury, namely a prolonged disorder of consciousness. This state has a very poor prognosis for survival. There is no prospect of recovery of any consciousness, and none of recovery to any state of independence. By definition this is now a chronic state. This is in keeping with the RCP guideline 2020 on PDOC, and the American Association of Neurology guideline 2018. With absolutely no trajectory of behaviours to declare even minimal awareness, this is highly likely to become a permanent state … His condition – general, systemic, and neurological – is poor. There is evidence of critical dysfunction and a dis-integration of several organ systems, contributing to a failure of the organism to function "as a whole"."

23. On his second visit, as recently as 14 July 2023, Dr Hanrahan noticed, "a substantial difference to his overall picture. While well nursed there is a tableau of increased frailty, morbidity and an increased effort of care needed to keep him at baseline … There is a palpable toll on caring nursing staff who feel that they are not really helping him anymore, but would look after and care for him unto the last. They would like to care for him in the event of a terminal care plan being sanctioned by the Court, taking advice from the palliative Care team." In his supplemental report Dr Hanrahan describes IN as being in a "permanent vegetative state. His prognosis is even poorer. He is closer to death despite current treatments that keep him alive… He has a very limited life expectancy of a few months." As already explained, Dr Hanrahan would in fact prefer the label "permanent coma" because of the absence of an established sleep-wake cycle. Dr Hanrahan approves of the step by step withdrawal of care plan and the provision of palliative care to be regularly reviewed. He believes that the best place for this to be implemented is on IN's current ward. Dr Hanrahan's view is that IN would be likely to die earlier than would otherwise be expected with discontinuation of CANH alone: "The severity of his underlying neurological, respiratory and cardiac states are already well declared and are likely to be the immediate cause of death as opposed to the 'withdrawal' of CANH."

24. Dr Hanrahan reported that the nurses caring for IN felt that there was a potential for suffering. Dr Hanrahan did not feel that he was suffering and is confident that IN will not experience pain or distress if CANH is discontinued. He will have no sense of being starved, for example. He considered that the grimacing noted is a neurological phenomenon seen in severely neuro-compromised patients – it is not an expression of emotion. Dr Hanrahan thought that the prognosis on withdrawal of CANH would be at the lower end of the one to three week survival prognosis given by Dr A, because of IN's physiological compromise due to his heart condition and diabetes. During the withdrawal of CANH, Dr Hanrahan would keep the tracheostomy in situ but deflate the cuff. Secretions would not be problematic due to the lack of hydration, and a dry mouth would be managed with mouth care.

25. Dr Hanrahan discussed IN's condition and treatment options with the family members. He says that he was clear that it was not his role to "evangalise them out of their strongly held beliefs" but he did explore them with the family members, and raised the question of whether discontinuing treatments that are futile and burdensome was at odds with the Christian doctrine of the sanctity of life or whether it "fulfils the theology of Creation and the Resurrection." After holding discussions with AN, Dr Hanrahan observed that "while she understood the seriousness and even permanence of [his] condition, it would be totally against hers (and his) belief system to lose hope. It was a value which if she did not have would make her less Christian. Therefore, accepting or acquiescing to any conversation that denied him even the slimmest chance of recovery, was unacceptable. He said, "She remained calm, eloquent and respectful throughout. It was clear to me that there would be no movement on her position."

26. Dr Hanrahan explored the family members' beliefs, and their views about IN's beliefs and values with sensitivity and he emphasised that this is not a difficult family but a family in difficulty. He observed that CANH is not a natural way of receiving nutrition or hydration - it is artificial.

27. Dr Hanrahan described the chronicity of the coma suffered by IN as being very unusual in his considerable experience.

Visit

28. I offered to visit IN at Hillingdon Hospital if the parties wished me to do so. In response the lawyer for the Official Solicitor accepted the offer, writing that whilst it would not assist as regards IN's participation, given his unconscious state, "the visit will allow His Lordship to observe IN's current presentation and his surrounds, and the visit may also be seen a signal of respect which may assist his family…". I visited IN in the late afternoon of 20 July 2023 in the company of a representative of the Official Solicitor who took a note of the visit subsequently shared with the parties on the morning of the hearing. I was shown to IN's bedside by an Occupational Therapist who had cared for him since his admission to Hillingdon Hospital. He shares a room with three other male patients. He cannot leave his bed – attempts to support him in a chair have been unsuccessful. He now has some pressure sores which are being managed by a Tissue Viability Nurse. The area around his bed was unadorned save for an iconographic image fixed to the wall behind him. IN was unresponsive whilst I was present at his bedside for about 15 minutes.

Submissions

29. The Trust has confirmed that if the court gives its consent on IN's behalf to continue CANH, it will provide it but with a view to then transferring IN to a nursing home with a gastrostomy in situ. This is not a case where the court would have to consider alternative care providers. The Trust submits that it has applied the appropriate national guidance for a patient with PDOC, and has tried to reach agreement with the family members but has not been able to do so. In detailed written submissions Mr

Hadden maintains that there is clear, cogent evidence that it would no longer be in in IN's best interests to continue to receive CANH, antibiotics and insulin and for him to commence palliative care. The Official Solicitor representing the interests of IN supports the Trust's application. AN and MN oppose it: they say that IN would have wanted his life to be in the hands of God, not for his death to be decided by doctors or the Court. He was a fighter who would have wanted to live as long as he could. A miracle might yet happen if he is allowed to live.

Conclusions

30. IN lacks capacity to conduct the proceedings and to make decisions about his care including the provision of CANH. A best interests decision has to be made on his behalf. The treating clinicians and IN's family cannot agree on whether continued CANH and other life-sustaining treatment is in his best interests and so the Court is invited to make the decision. That is a sombre responsibility. I have received helpful evidence from Dr A and Dr Hanrahan, and from AN and MN. I visited IN in hospital. I have considered very carefully the submissions made. My role is to apply the legal principles as set out above, including the burden and standard of proof. I have to analyse the competing issues and balance them when determining not just IN's medical condition and prognosis, but his best interests in the widest sense.

31. First and foremost is the presumption that all reasonable steps should be taken preserve his life. However, if analysis of all the relevant evidence and considerations demonstrates that IN's best interests would not be served by continuing CANH then the presumption will be displaced.

32. The evidence establishes that:

    i) IN has a prolonged disorder of consciousness that might be described as a permanent coma. He will not recover full any level of consciousness nor any independence.

    ii) IN will remain bedbound and fully dependent on nursing care for all his functions.

    iii) The trajectory for IN's condition is in fact one of deterioration as witnessed by Dr Hanrahan.

    iv) I would hesitate to call CANH "futile" in that it is treatment that can help to keep him alive, potentially for a few months, but there is no treatment that will improve his condition. Treatment may prolong life and ease his burdens but it will not change the trajectory of deterioration.

    v) It is unlikely that IN will survive more than three to six months even with continued CANH and antibiotic support when needed.

    vi) The ongoing interventions for IN include insertion of an NG tube attached to his face through which he receives feeds, a tracheostomy that has to be changed every few weeks, a catheter for drainage of urine, blood tests to monitor for sepsis, electrolytes and nutrition. He has a PICC line but

sometimes venepuncture is required to take a blood sample. He undergoes frequent suctioning to avoid aspiration. He is incontinent of faeces two or three times a day and requires nursing care to clean him. He has pressure sores to his lower right leg and heels which require management from the Tissue Viability Nurse.

vii) IN's quality of life is very poor – he is doubly incontinent, he has general oedema, he has pressure sores, he has to accept the interventions set out above. He is unaware of people or the environment around him. He can take no pleasure in the company of others or stimulation of any kind. In its detailed document entitled Supporting Information for Decisions to Withdraw CANH (page 33 of the bundle) the Trust has noted,

> "Sadly, there are no signs of enjoyment or positive emotions. Incorporating meaningful and positive stimulation (i.e. playing his favourite music, using the scent of his favourite toiletries, opportunity for his family to visit/talk to him via videocall) would optimise the conditions for potentially positive experiences."

But there have been no signs of responses even to those stimuli.

viii) It is possible, but unlikely that IN can suffer pain. He has been noted to grimace at certain times, for example when his tracheostomy has been changed. However, when bloods have been taken via a needle he has been seen to grimace but also not to grimace. Therefore, there is no consistency of response. If he does suffer pain or discomfort it is at an unconscious level, as if a reflex response.

ix) There would be no benefit or need for further testing or assessment – IN has been fully and repeatedly assessed over several months.

x) On the step by step withdrawal of CANH plan being implemented, IN would probably die by about one week but there can be no certainty about that prediction. He would be very unlikely to survive for more than three weeks.

33. I am satisfied that key clinical guidance: The Royal College of Physicians Prolonged Disorders of Consciousness following sudden onset of brain injury 2020 and the Joint Guidance published by the BMA, RCP and GMC, *Clinically assisted nutrition and hydration and adults who lack the capacity consent* (2018), have been applied.

34. Even if IN cannot experience pain, it does not follow that continued treatment is not burdensome – see King LJ in *Re A (A Child)* [2016] EWCA Civ 759, and Baker LJ in *Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust* [2021] EWCA Civ 362, at [61]. IN's condition and the interventions required to keep him alive are burdens even if he is unaware of them. In like manner, I should also consider the wider benefits to him of continuing CANH even if he is unable to experience pleasure. Sadly, because of family circumstances, he is not surrounded by his loved ones day in day out, he is on a ward with three other patients, he benefits from the devoted care of the staff and his family make contact with him as and when they can,

but it is difficult to identify wider benefits to him from continuing CANH beyond the bare fact that it will keep him alive for, at most, a further few months.

35. It is not possible to ascertain IN's wishes and feelings. Ms Sutton KC for the Official Solicitor cautions against speculating too much about what IN's wishes and feelings would now be. He very probably lacks the capacity to summon conscious wishes and feelings. It would be wrong, in my judgment, to project on to him wishes and feelings based on what he has previously said or done, because he may very well not have contemplated being in the parlous situation he is in now. In any event there is no evidence that he has previously expressed a wish about what should happen to him in this kind of situation. I do however have to take into account the beliefs and values that would be likely to influence his decision if he had capacity, and the other factors that he would be likely to consider if he were able to do so. I have no doubt that those would have included his Christian faith and his commitment to putting his family, in particular his daughter, first. However, it is not obvious that those beliefs and values would have translated themselves into a choice to continue with CANH. His own beliefs and values may have led him to protect his daughter from witnessing his continuing suffering, or to put himself into the hands of God rather than continuing to be kept alive by the hands of healthcare professionals. As AN has said, he would then give his life to God, not to man. The views of AN and MN as to IN's values and beliefs are important, but I have to be careful not to confuse their own values and beliefs with those of IN. Their own beliefs may well inform their views of what is in IN's best interests but they are not necessarily the same as IN's own beliefs. Nevertheless, they are in a better position than anyone else to inform the Court of IN's own beliefs and values. I accept their evidence that IN was a man of faith who believed that we live and die to the Lord.

36. I must take into account that IN may have only a few months to live even if CANH is continued. The burdens of his condition and treatment will therefore be unlikely to last for many years ahead. On the other hand, (i) those burdens will continue for as long as he lives, and (ii) he will be more likely to die due to an infection, or a sudden respiratory or cardiac arrest. If the step by step withdrawal of care plan is carried out then he is likely to die in perhaps a week or so, but his care will be planned and carefully managed to cause him the least possible distress, if he can feel distress, to provide him with palliative care, and to allow him a peaceful death. In this context I do not find it helpful to co-opt the notion of "dignity" - to suppose that the managed withdrawal of life-sustaining treatment as opposed to continuing such treatment enhances innate human dignity. He would not be in "anguish" as his daughter has said she fears. The plan for palliative care is designed to prevent that. For some, there is dignity in a managed death, for others there is dignity in fighting for life and survival. Human dignity is a very important concept in decisions about end of life care and it is recognised and respected by application of the principles in the MCA 2005 and the authorities, and by an intense focus on IN's best interests. However, based on the evidence I have received about IN's character, I am sure that he would have preferred a peaceful death if only to protect his family from avoidable distress.

37. I must take into account the views of AN and MN as to what is in IN's best interests. AN has said in her email to the Court that it cannot be in IN's best interests to let him "die slowly, not because he is sick but because he doesn't have any water or food in his body." Unfortunately, he will die more slowly if CANH is continued rather than

withdrawn. The evidence is clear that he will not suffer any more from the withdrawal of CANH than he does from being kept alive with CANH. However, AN's views are of importance as are those of MN.

38. I must also take into account the views of the treating healthcare professionals as to IN's best interests. The evidence before me is that there is unanimity amongst them that the proposed withdrawal of care plan is in IN's best interests. Day by day they care for all his needs. They did not know IN before his stroke, but they know the most about him in his present state. They are very well placed to gauge whether continued CANH is of benefit to him. Dr Hanrahan reports that the toll on the healthcare professionals caring for IN is "palpable", not because they would not continue to provide a high level of care for him, but because they view it as futile and against his best interests.

39. The withdrawal of care plan is carefully worked through. It would allow for the family to attend on IN and for a Romanian interpreter to be provided. The tracheostomy will be kept in situ. Palliative care including morphine and midazolam would be provided. A four stage process has been planned. The family will be kept informed at every stage and the plan will begin only when they have had a reasonable opportunity to travel to be with IN. A single bedroom will be used. A priest will be arranged to attend if that is what the family wish.

40. The best interests exercise adopted in this case ensures that IN's Convention rights under Arts 2, 3 and 8 are fully considered and respected.

41. Weighing all these considerations in the balance I conclude, with sadness, that this is a case in which the presumption that life should be preserved is displaced by the weight of countervailing factors, most particularly the very profound brain damage which has left IN in a permanent coma from which he is highly unlikely to emerge even to a vegetative state, the inability to experience pleasure, the burdens of his condition and continued treatment and the absence of any prospect of improvement. I do not find it possible to ascertain IN's own wishes and feelings. His values and beliefs may or may not have led him to decide to continue CANH had he retained capacity. The views of his family members about his best interests and his values and beliefs weigh in favour of continuing CANH, but not to the extent that they outweigh the other factors supporting the withdrawal of treatment.

42. I have sought to step back and to consider IN's best interests in the widest sense. In doing so I conclude that it is not in his best interests to continue to receive CANH. Accordingly, the withdrawal of CANH in accordance with the step by step withdrawal of care plan is in his best interests and is lawful. Putting it plainly, he has no prospect of recovery and the provision of CANH will only prolong his burdens and give him no benefit. Even though his life expectancy with continued CANH is relatively short, for so long as he is given CANH, his burdens are continued.

43. The current plan is to leave IN's tracheostomy in situ. Although that may have the effect of prolonging his life by some days, I do think it is in his best interests to keep the tracheostomy in place – IN's values are such that he would not have wanted his family or staff to witness his struggling for breath for a period that might last for a week or more were the tracheostomy removed. That is what I believe would have been in accordance with his values as relayed to the court by his family. Whilst he

will continue to suffer the burdens of his condition and interventions including the tracheostomy for as long as he is alive, he will receive palliative care and so the Court can be as sure as it is possible to be, that IN will not experience pain or distress whilst the plan is implemented. On balance I consider that the plan to maintain his tracheostomy is in his best interests.

Transparency Order

44. Following the Court of Appeal decision in *Abbasi v Newcastle Upon Tyne Hospitals NHS Foundation Trust and Ors* [2023] EWCA Civ 331, it is necessary to reconsider the terms of the Transparency Order (TO). I agree with Mostyn J in *Re EM* [2022] EWCOP 31, that a TO, the order "ordinarily" made when it is ordered that proceedings be heard in public, is a reporting restriction order. It is the TO that allows the proceedings to be heard in public, but it nevertheless restricts what can be reported. Although a TO will "ordinarily" be made and will "ordinarily" be in the terms of the standard order approved by the President of the Court of Protection – COP PD 4C – the authorities, including *Abbasi*, demonstrate that the Court is still enjoined to carry out a balancing exercise involving consideration of Article 10 and Article 8 Convention rights – the balancing exercise described in *Re S* [2004] UKHL 47; [2005] 1 AC 593.

45. *Abbasi* concerned the "modern practice in the Family Division of the High Court of granting indefinite anonymity orders to a wide range of medical (and non-medical carers" in end-of-life cases in the High Court. The Court of Appeal commended the approach taken by Lieven J in the *Abbasi* case of limiting the duration of the anonymity given to the Applicant Trust in that case and placing the onus on the Trust to seek an extension, and on focusing on a limited number of individuals who required protection. They also commended the approach in *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164; [2020] 4 WLR 52 where the extension of the reporting restriction order was limited by consent to a period of 28 days after the removal of ventilatory support, subject to further application. The Court of Appeal observed that "there will be different considerations affecting protecting the long-term anonymity of family members if their identities are not in the public domain and they seek protection." [128]. It seems to me that the decision in *Abassi* applies equally to the Court of Protection where TOs are commonly made to cover a wide range of healthcare professionals and to last "until further order".

46. The TO made by Moor J at the outset of these proceedings prohibits the publication and communication of information that identifies or is likely to identify IN, that any person is a member of his family, "other attendees", where any such people live or are being cared for, the Hospital, and the "staff in relation to IN's care and treatment." The injunction is to "have effect until further order of the Court."

47. I have considered submissions in relation to the TO and have carried out the four stage process identified by the President of the Family Division in *Abassi*, [2021] EWHC 1699 (Fam). This involves an intense focus on the Art 8 and Art 10 rights engaged. This case has not previously been the subject of reporting. Information is not already in the public domain. The family members have expressed no wish to publicise matters in or arising from this case. However, there is an interest in such

Court of Protection proceedings involving end-of-life decision-making. This is not a case where there has been adverse commentary on social media or elsewhere directed to the hospital or healthcare professionals. There are only a few healthcare professionals whose identities are relevant to the proceedings. It is important that those professionals feel enabled to carry out their functions without the fear of hostility. It is a fact that whilst some will regard it as unethical to continue CANH in a case such as this, others will regard the withdrawal of CANH as unethical and deserving of condemnation, including personal condemnation of those responsible. Of course, Judges who make these decisions are named but healthcare professionals are more commonly involved in these difficult decisions and it is important that they are able to make those decisions free from untoward interference. In the present case the Trust invites the court to discontinue the injunction against reporting in relation to the hospital and the identified clinicians at the hospital until after IN's death. I shall direct that those parts of the injunction shall be discharged 7 days after IN's death unless there is a further or other order of the court. The reporting restrictions in respect of IN and members of his family shall remain until further order. AN does not wish IN to be identified. MN was content to leave that decision to the Court. I am satisfied that the continued anonymisation of IN, and therefore of members of his family (to avoid jigsaw identification) will not so adversely affect the Art 10 rights of those who wish to comment or report on this case as to justify what would be a significant interference with the Art 8 rights of IN's family were his and their names to be made public. Accordingly, the TO will remain in place until further order in relation to the identification of IN and family members. I shall delete the reference to "attendees" in the TO – it was not made clear to me who those persons were (beyond the clinicians and the family members). Dr Hanrahan, as an expert, may be named. I vary the TO accordingly.

Postscript

I gave this judgment in open court on 21 July 2023. Very sadly IN died in hospital on 24 July 2023. This was before the implementation of the plan to withdraw CANH. I have offered my condolences to his family who raised no objection to this judgment to be published.