Neutral Citation Number: [2024] EWCOP 35 (T1)

Case No:

COP1401724T **IN THE COURT OF PROTECTION**

Royal Courts of Justice Strand, London, WC2A 2LL

Date:

05/07/2024 **Before** :

MRS JUSTICE THEIS DBE
Vice President of the Court of Protection

- -

Between :

	NHS NORTH WEST LONDON INTERGRATED CARE BOARD ("the ICB")	**Applicant**
	- and -	
	Z **(by his litigation friend, the Official Solicitor)**	**1st Respondent**
	- and -	
	The Royal Hospital for Neuro- disability ("the RHN")	**2nd Respondent**

- -

Mr Jake Rylatt (instructed by **Capsticks**) for the **Applicant**
Mr Patel KC (instructed by **the Official Solicitor**) for the **1st Respondent**
Ms Katie Scott (instructed by **Bevan Brittan**) for the **2nd Respondent**

Hearing dates: 27th and 28th June 2024
Judgment: 5th July 2024

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Approved Judgment

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MRS JUSTICE THEIS DBE

This judgment was delivered in public, but a Transparency Order dated 5 July 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 Z 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. The court is dealing with an application brought by the NHS North West London Integrated Care Board ('ICB') for an order that permits the withdrawal of clinically assisted nutrition and hydration ('CANH') to Z age 70 years. That application is supported by The Royal Hospital for Neuro-disability ('the RHN'), by Z's sister, X, and one of his close friends, Y, and opposed by his wife, W, and another of his close friends, V. Having had the opportunity to hear the evidence the Official Solicitor, on behalf of Z, supports the application.

2. Until 2021 Z was someone who lived life to the full. He embraced life in every sense of the word, in particular the outdoors. He was an accomplished scuba diver, pilot, sailor, a much loved brother, a true friend and a devoted husband. The court has had very powerful evidence from his sister, two of his close friends and his wife. They all spoke as one about Z's character, his sensitivity, concern for others and his curious and inquiring mind. In addition many other friends attended the hearing in support, demonstrating how much he is loved by so many. Although W, X, Y and Z were not parties to the proceedings they each took an active part in the hearing and W has had the benefit of an experienced solicitor, Ms Hobey-Hamsher, to speak to when she needed to. Ms Hobey-Hamsher acted pro bono in providing that advice and assistance, for which the court is very grateful.

3. There is no issue about Z's current medical position, or that he lacks capacity to conduct these proceedings or make decisions about his treatment. The court has evidence from the clinical team at the RHN and the benefit of a second opinion from Dr Nair, Consultant in Rehabilitation Medicine, and an independent expert report from Dr Barry, Consultant in Palliative Medicine. Dr H, Consultant in Neurorehabilitation Medicine at the RHN, gave oral evidence as did Dr Barry, together with X, Y, V and W.

4. What is in issue is whether it is in Z's best interests for CANH to be withdrawn or for him to continue in receipt of that treatment. Whilst the RHN support the withdrawal of CANH it has made it clear that if the court refused the ICB's application Z would remain in receipt of CANH.

5. I had the very great privilege of going to visit Z the day before this hearing in the company of Mr Edwards from the Official Solicitor. I had the opportunity to read the papers before that visit and the detailed attendance note from Mr Edward's last visit to Z in April. I was shown round the grounds by members of the clinical team, briefly saw W and spent some time with Z. He was in his wheelchair by his bed, surrounded by photos of his family, friends and his many adventures during his life. A picture was painted for me of what his day to day life consists of. Z appeared calm, stable and restful for most of the time when I was there.

Relevant background

6. Z enjoyed excellent health until 2021 when he had a calf melanoma excised. Following that a right tonsil carcinoma was incidentally picked up, for which the plan

was for Z to undergo surgery to remove the cancer, followed by adjuvant radiotherapy. Z had the surgery in September 2021. Tragically, nine days after surgery Z suffered a major haemorrhage from the surgical site. Due to the severity of the haemorrhage he suffered a cardiac arrest which resulted in global severe anoxic hypoxic brain injury. A tracheostomy was formed and a percutaneous endoscopic gastronomy ('PEG') was inserted for the provision of CANH. A 'Do not attempt cardio-pulmonary resuscitation' direction was placed in October 2021 and a wardbased ceiling of care.

7. A referral was made to RHN for an inpatient admission to the Brain Injury Service but it was agreed that the RHN's specialist nursing home would be more suited to Z's needs. In early December 2021 funding was requested for admission to a specialist nursing home bed at RHN with the following recommendation: *'[Z] will be reviewed as part of our MDT annual review process for individuals in a PDOC as per the recommendations by the Royal College of Physicians. This will include: completing PDOC assessments and comparing results with previous ones to see if there has been any change; should any change be observed, follow up sessions with OT will be provided to explore whether [Z] has the potential for functional communication or activity participation'*.

8. Whilst Z remained in the acute hospital he underwent weekly assessments of his consciousness and was identified as being in a Prolonged Disorder of Consciousness ('PDOC') and was, in all probability, in a continuing vegetative state at that stage. Clinically the assessments did not change and appeared to be diagnostic of a vegetative state without any trajectory of behaviours along the spectrum of consciousness. MRI investigation confirmed severe and well established widespread damage to his entire brain, in keeping with further progression of his hypoxic brain injury.

9. Z was moved to the specialist nursing home within RHN, (in December 2021, where he remains. The RHN is an independent charity and one of the largest centres in the United Kingdom for providing care, treatment and support to those with complex and sometimes profound neuro-disabilities. The specialist nursing home at the RHN is described as being more akin to a community nursing home *'albeit one which is highly specialised in caring for patients with very specialist and complex needs'*. There is a team of GPs (from an external GP practice) who provide GP services to the residents and who have overall clinical responsibility for them.

10. Z is provided with treatment and care via a multi-disciplinary team ('MDT'), including his GP Dr C, neurorehabilitation consultants, occupational therapists, physiotherapists, speech and language therapists, dieticians and nurses. In addition, Z's MDT has advice and assessment from Dr H, Consultant in Neurorehabilitation who is the Clinical Neuro-Palliative Lead for the RHN.

11. On 8 February 2023 W agreed with the treating team's decision that a ceiling of treatment should be in place that Z should not have cardiopulmonary resuscitation or further antibiotics. This is the current Treatment Escalation Plan ('TEP').

12. Z underwent further PDOC assessments, in accordance with the Royal College of Physicians *Prolonged disorders of consciousness following sudden onset brain injury: national clinical guideline* (2020) ("RCP PDOC Guidelines"). Those

guidelines consider the response patients have to various stimuli. The assessments are:

(i) The Wessex Head Injury Matrix ('WHIM') is an observation tool used to highlight responses to sensory stimuli. It consists of a series of bedside observations, undertaken by trained observers, who score a hierarchy of emerging behaviours post brain injury, in order of significance. The higher the score the more likely awareness exists. The highest score is 62.

(ii) The JFK Coma Recovery Scale – Revised ('CRS-R') is used to measure specific behavioural responses to stimuli. There are 25 hierarchically arranged tests with six subscales. The highest score is 23.

(iii) The Sensory Modality Assessment and Rehabilitation Technique ('SMART') looks at motor and communication responses across the five sensory modalities. This is used to provide an indicative diagnosis of vegetative state, minimally conscious plus or minimally conscious minus and also indicates any likely emergence.

13. Following his transfer to the RHN Z was further assessed in accordance with the PDOC Guidelines using the WHIM and CRS-R methods of assessment over three separate 3 – 4 week periods, the most recent being in May 2024. Each assessment concluded Z remained in a PDOC at a level of vegetative state. During the assessments Z's eyes were noted to be closed with some partial opening and eyelid flutters, his eyeballs were noted to be roving behind closed eyes and his lip was noted to twitch. His arousal was overall low; he opened his eyes to stimulation (loud noise, music or being touched). Some grimacing was noted outside of the assessment in response to sound or music without differentiation. Dr H describes some other behaviours noted by staff and Z's wife including yawning, head and neck movements to sound with no consistency to suggest they were localising behaviours, facial features to suggest muscle relaxation when music was played, some escape of tears from his eyes, grimacing in response to sound, and what was described as 'silent crying'.

14. Dr H sets out in his evidence that none of these behaviours are inconsistent with the vegetative state. They do not indicate an awareness, and interpretation in isolation runs the risk of confusion as family and carers may understandably interpret them as recovery, whereas in reality these are what Dr H describes as *'rudimentary neurological phenomena denoting varying arousal, arising from the devastating destruction of all awareness networks, with some preserved arousal.'*

15. In May 2023 Dr A, PDOC physician at RNHD, concluded that Z was in a permanent vegetative state ('PVS') with a life expectancy of 2 years.

16. Dr H assessed Z in November 2022 and confirmed then he was in PDOC and was in all probability in a continuing vegetative state. He reassessed Z in May 2024 through further observations, consideration of his records including any impact his medication may have. Dr H was satisfied that none of the medication would impact on Z's neurological status, including the beer through his PEG as agreed between Dr C and Z's wife. Dr H looked at whether any environmental circumstances could affect Z's awareness but concluded none would have made or will make any difference to his neurological presentation. Dr H considered Dr A's previous assessment and

concluded Z is in a vegetative state and as there had been no trajectory of behaviours since onset in September 2021 he concluded this is a PVS.

17. Dr H's view is that Z's life expectancy is between 5 – 7 years. This could be shorter if there was an acute event, such as respiratory infection due to the current treatment escalation plan ('TEP'). As Dr H states *'It is highly likely that [Z] will deteriorate during his life even with excellent nursing care; this is a complication of his brain injury, the resulting immobility, and complications. He is growing older with a brain injury'.*

18. Z's wife, W, visits almost every day and stays for most of the day from 11am to 8pm. She works closely with and in conjunction with the clinical team and supports their care of Z in any way she can. When Mr Edwards visited on behalf of the Official Solicitor W was massaging Z's legs as she does regularly. W takes Z out into the garden each time she visits, rain or shine, so he can experience the outside which he so loved throughout his life. W provided the court with a number of photos of Z outside in all weathers.

19. Since March 2023 RHN have held a number of meetings with W and sought the views of Z's family and friends about Z's continuing treatment. They have agreed a TEP, the effect of which is that Z would not be given CPR in the event of a cardiac arrest or given antibiotics in the event of an infection. He would also not be transferred to an acute hospital. The final RHN Best Interest decision record and checklist dated 11 May 2023 has documented the views of the family and treating clinicians. The record of the meeting notes *'The clinical team feel that a clear picture has been painted by those who know him best that [Z] was a very active man who lived a full and rich life and shared a great love with his wife. His family and friends agree that he would not want his life to be perpetuated in this situation – the disagreement about what he would want for himself is focussed on the mode of death. The clinical team feel that he would not choose to prolong his life in a vegetative state if he was able to chose for himself, and that to discontinue CANH is in his best interests….the decision maker (GP – Dr C) is unable to make a best interest decision at this time as there is a disagreement between those consulted about what is in [Z's] best interests regarding CANH discontinuation. Although all agree that [Z] would not want to live in this state, there are disagreements about whether or not he would want withdrawal of CANH to be the mode of death'.*

20. Following the meetings there was no consensus reached about the RHN clinical view that it was in Z's best interests for CANH to be withdrawn. As a consequence, the ICB made this application on 27 March 2024. Following directions made on 4 April 2024 and 3 May 2024 this hearing was listed.

21. Prior to this hearing the palliative care plan ('PCP') was updated to take account of the report from Dr Barry, in particular to provide an alternative to morphine as it was known Z did not like taking morphine.

22. Z's current position is that his tracheostomy, which was formed as an emergency, is now used to assist with the management of mucus in his chest and may help to reduce the risk of chest infections from saliva entering the lungs. He can have thick secretions and is prescribed medication to help break up the mucus to make it easier to clear them from the respiratory system. Z has a strong cough and secretions are

removed via a suction device into the tracheostomy tube, which is observed to cause Z discomfort. Z has a 24 hour postural management programme, his skin is dry and

fragile and at constant risk of breakdown. He is nursed on an air mattress and is turned every 4 – 6 hours.

The evidence

23. The bundle includes statements from Z's key clinicians at the RHN, in particular Dr C, his GP, and Dr H, the expert reports from Dr Nair and Dr Barry and the statements and emails from W, X, V and Y. Dr H, Dr Barry, W, X, V and Y gave oral evidence.

24. In his oral evidence Dr H expanded on a number of matters referred to in his statement. He set out the reasons why the RHN did not support removal of Z's tracheostomy and that it was not a treatment that was being offered to Z and so is not an option for the court to choose. Z has been dependent on his tracheostomy since his brain injury in September 2021. There have been no formal attempts to wean him off this device. That was the advice given from the acute hospital and continued on his transfer to the RHN due to the nature of his primary malignancy and neck surgery.

25. The tracheostomy protects Z's airway but it is unclear whether the patency of his airway is dependent on it, it is not known whether he would be able to breathe without it. To remove it would be a step into the unknown as whilst Z may die relatively quickly he may not and he may continue breathing independently for some time. It is not possible to remove a tracheostomy and 'see what happens', consideration would need to be given to the nature of the weaning process (which could take several months to a year) and to justify the purpose of doing it.

26. In Dr H's view the tracheostomy is currently well managed and removal could introduce unnecessary unpredictability in managing Z's airway. It would be highly likely to increase his respiratory effort, work of breathing, and physiological distress. In Dr H's view that situation would be very difficult to manage clinically bearing in mind the TEP. Dr H recognised that there is an ongoing burden of care in managing the tracheostomy, the most significant of which is the suctioning that is required on average about 6 times per day, but can sometimes be double that frequency. If the tracheostomy was removed Dr H's evidence was that it would not be clear Z would die, there is a chance he could continue to breathe and the support required to enable him to do that would be disproportionate at every level and could include Z drowning in his own secretions and may take months.

27. Dr H also addressed deflating the cuff of Z's tracheostomy as part of the PCP if CANH is discontinued. The purpose of the inflated cuff on a tracheostomy is to reduce secretions creeping down into the lung from the throat above the cuff. If the main tracheostomy and inner tubes get blocked with thickening secretions, there would be no airway available and any patient will quickly go into respiratory arrest. If the cuff remained inflated to ensure there were no blockages to the tubes Z would have to be examined and monitored continuously connected to a monitor and alarm, with frequent clinical interruptions. The aim of the PCP is to ensure that as far as possible Z remains calm, pain free with as little medical intervention as possible.

28. Dr H recognised that if CANH is withdrawn then the ensuing dehydration combined with changes in Z's medication would mean there is an increased risk his secretions would be thickened and may block the inner tube of his tracheostomy. This may result

in Z struggling to breathe which could result in additional intrusive medical intervention, including suctioning. By deflating the tracheostomy cuff, if it can be tolerated, the likelihood of blockages is reduced as is the need for intervention.

29. As regards the updated PCP Dr H emphasised the need for flexibility to manage changing clinical decisions at the time and emphasised the need for the plan to be proactive to minimise any distress. Dr H recognised the concern expressed by W about Z experiencing hunger and thirst if CANH is withdrawn. In his opinion, due to the nature of Z's condition, it is unlikely hunger and thirst would be sensations Z would perceive. Dr H emphasised the importance of good mouth care and to keep mucus membranes moist. He recognised there would be noticeable changes, for example Z's skin would change, he would have a more gaunt appearance. Dr H's view was Z would not become skeletal, as feared by W. The purpose of the PCP is to proactively alleviate as much as possible so that a calm environment can be achieved for Z to enable him to die in peace and with dignity with his family and friends there, if they wished, supported by the experienced clinical team.

30. If CANH was withdrawn Dr H considered Z would die in between 1-3 weeks. When asked by Mr Patel K.C. if there were any other alternatives to the choices faced by the court Dr H confirmed there were not. In relation to the PCP Dr H confirmed that in the early stages of that plan it would be possible for Z to be taken outside by W but would then need to reassess, particularly regarding risk of pressure sores in the wheelchair. If there was withdrawal of CANH Dr H confirmed that the cause of death on the death certificate would reference the original cause, namely the brain injury.

31. Dr H's evidence is supported by the statement from Dr C, Z's GP.

32. In her evidence Z's sister, X, powerfully stated that she believed *'there is a consensus between all of us who deeply love [Z] that he would not want to be in his current state'.* She recognises the very high standard of care for Z by the clinical team and W but continues '*I am so painfully aware that [Z] is kept in a situation where he has no choice, no privacy, no independence, no way to interact and engage with others, no chance to experience and adventure in the world either physically or mentally, all of which are things he so highly valued his whole life'.* In her view Z would, like most of us, want *'a quick painless passing, knowing how [Z] was also very practical and pragmatic I believe that given all the aspects of this tragic situation and available options now he would not see a managed withdrawal of the CANH as the worst thing and that he would consent to this.'*

33. Z's two friends Y and V take different views. They had each known Z most of their lives. Y movingly described how Z would add to the life of others he met through his thirst for learning and inquisitive mind. He was someone who was happy in company but also equally content in silence. Y was clear in his mind that Z would not have wanted to exist in the way he has over the last 33 months. He would not want to be a burden to others and would be keen to relieve the burden his position was causing to others, especially those nearest to him. In his words he considers Z *'would want to exit to see what is on the other side'.* V took a different view, that Z would want to put W first, that withdrawal of CANH would not be a quick death which he would not want W to witness. V believes he would support what W wishes for, namely Z to live until he dies a natural death.

34. Although at times deeply distressing for her, W bravely and courageously read her statement which set out her views in unequivocal terms. She describes Z's relative stability, what she considers would be Z's wishes and feelings and how difficult she has found the discussions with the clinical team about Z's best interests. W is clear that of the choices facing the court Z *'would want to remain how he is in his current condition, and to be allowed to die in his own time in a dignified and natural manner'*. In her statement she sets out her fears about what would happen to Z if CANH was withdrawn and compares that to how Z is now. Her view is summarised in her statement as follows *'[Z] would want a natural or quick and instant death – a dignified death. Not what is being proposed. And if those are the only two options, I believe that he would want to remain in his current condition until he has a natural death. No one really knows what is in the mind of a patient in a vegetative state.'*

Expert evidence

35. Both Drs Nair and Barry were instructed to provide their opinions in their respective fields of expertise.

36. Dr Nair was asked to review Z, provide a diagnosis and prognosis report with a specific section on his level of awareness/responsiveness and a current diagnostic assessment of PDOC and Z's potential for recovery and prognosis with or without CANH and whether it was in Z's best interests to continue with CANH. His report is based on his review of the papers and medical records, his own assessment of Z on 17 February 2024 and his discussion with W and X. He concludes his report as follows:

'I would refer to paragraph 30 of the BMA and RCP guidance on CANH in PDOC 'The central point to keep in mind, throughout the decision-making process, is that the decision is about what is in the best interests of the individual patient, not what is best for those who are close to them, what most people in their situation would want or what is best for the family, the care team, or the providers or funders of care.' The irrefutable facts are as follows:

1. *[Z] has suffered very severe hypoxic brain injury. MRI scans done 46 days after the index event already show evidence of damage and atrophy.*

2. *2 years and 5 months post the hypoxic brain injury despite multiple assessments, the most consistent category of PDOC that is applicable to [Z] is a permanent vegetative state. The number and detail of these assessments meet the recommendations of the RCP guidance of PDOC.*

3. *Having reviewed the statements of friends and family and after speaking to the family my conclusion is that his wife [W] is torn between what she wants for [Z] from what is in his best interests. There has been adequate consultation with friends and family and level of documentation I have seen is in line with the guidance from the RCP and BMA guidance on best practice.*

Therefore, I would conclude that on the diagnostic and prognostic evidence available, it would not be in [Z's] best interests to continue to receive Clinically Assisted Nutrition and Hydration.'

37. Dr Barry was asked to report on prognosis, palliative care plan, treatment escalation plan and tracheostomy care if the court declares that CANH is no longer in Z's best interests. She did not visit Z but undertook a review of the hearing bundle and RHN

records. In her detailed report she supports the conclusions of Dr H and Dr Nair and provides, in the event of a decision that it is not in Z's best interests to continue to receive CANH, more detailed alternatives for medication and management of the palliative care plan, in particular providing an alternative to morphine.

Legal framework

38. There is agreement between the parties as to the relevant legal principles.

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

40. 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]

41. Clinically Assisted Nutrition and Hydration ("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).

42. 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").

43. In *W v M* [2011] EWHC 2443 (Fam), Baker J (as he then was) expressed that this presumption can be *"simply stated but [is] of the most profound importance"* and "*carries very great weight in any balancing exercise*" (§222).

44. 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 lifesustaining treatment. Having enunciated this point, Lady Hale in Aintree v James [2013] UKSC 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 who life may continue for some time."

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

46. 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).

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

48. 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 lifesustaining 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 professionals 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).”

49. The holistic nature of the best interests analysis was expressed by Lady Hale in Aintree v James [2014] AC 591 as follows:

“*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”*. (§39)

50. 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”.

51. A number of cases have sought to provide a 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

52. In their written and oral submissions the ICB and RHN set out their analysis of Z’s best interests.

53. Mr Rylatt, on behalf of the ICB, recognises the strong presumption in maintaining Z's life and for CANH to be continued but, he submits, there are strong countervailing considerations, in particular regarding the numerous medical interventions that maintaining his current position requires, the risks inherent in an acute event and his poor baseline medical position which is only likely to deteriorate. As regards Z's wishes and feelings Mr Rylatt acknowledges that due to Z's current position it is not possible to ascertain those and it is not a situation that he had expressed a view on previously. However, there is unanimity of views that Z would not want to live in his current condition. W expresses her belief that Z would want a quick death rather than the delay and uncertainty if CANH was withdrawn and for W to witness that. She considers her view is fortified by researches Z made when he was first diagnosed with cancer about dying with dignity.

54. Ms Scott, on behalf of RHN, submits the evidence demonstrates Z is in a PDOC and at the lowest end of the spectrum of awareness. The burdens of his condition mean he has no ability to communicate, no purposeful movement, is doubly incontinent, suffers from spasticity and high tone in his limbs, has fragile and dry skin which is at risk of breakdown, has chest infections that have required antibiotics, multiple episodes of vomiting which whilst largely managed by medication still occurs at night, has thick secretions, has suffered from and remains at risk of pressure ulcers and is totally dependent on others for all aspects of his everyday life.

55. His treatment also carries with it considerable burdens. Due to his thick secretions his tracheostomy requires regular suctioning, it takes place between 6 and 13 times a day, and lasts 5 – 10 minutes. The procedure elicits a reaction from him including coughing and going red although Dr Nair considers that due to his condition Z has no conscious experience of pain. In addition, the tracheostomy has to be changed every 29 days which has its own risks. His PEG has required treatment for over-granulation and will need to be changed, which will require Z's attendance at an acute hospital. He is on considerable medication, which is delivered 4 times a day. He has nebulisers 3 times a day. Z has observations every day, personal care every day, needs to be turned every 3-4 hours and needs his incontinence pads changed a number of times each day.

56. As regards the benefits Z derives from his life at the moment there is some very limited evidence he may fleetingly respond to music but that does not change the overall diagnosis and prognosis.

57. Ms Scott submits the evidence is clear there is no prospect of any improvement. If CANH is not withdrawn Z's life expectancy is put variously at between 2 – 7 years. If

    CANH is withdrawn it is likely that Z would die within 1 – 3 weeks.

58. Ms Scott submits the burdens of Z's treatment and condition outweigh the benefits bearing in mind his diagnosis that he is in PVS. It is agreed this is a life Z would not want and there is no prospect of any change.

59. Mr Patel recognises, on behalf of the Official Solicitor, that there is no easy decision. The respective positions taken by W, Y, X and V are thoughtful and reflective. It is understandable why W takes the position she does, not on any hope that Z will recover in any way but due to her understandable and strong reaction to what she

regards as a slow, painful and undignified death if CANH is discontinued. That view is shared by V but not by X and Y.

60. Mr Patel considers there are two unusual features in this case. First, the objection to the discontinuation of CANH is based on the burden said to arise from the manner of death, even with palliative care in place, which was explored in the oral evidence. Second, the weight that should be afforded to Z's wishes that he would not want to place W in a situation which she would find painful and distressing.

61. At the start of this hearing the Official Solicitor did not take a position regarding the application, stating that she would review that after the conclusion of the evidence. Having heard the evidence the Official Solicitor supported the declaration that CANH be discontinued.

62. As Mr Patel put it in his oral submissions everyone would want a quick and instant death but that is not the reality in this case and the court needs to engage in a best interest analysis of what are the actual options.

Discussion and decision

63. The sad and tragic reality of this case is Z has no prospect of recovery due to the severity of the brain injury he suffered, with the consequence that he is in a permanent vegetative state. He is relatively stable at the moment, in the sense that he does not fluctuate but that is down to the highly skilled clinical care supported by the consistency of the devoted care provided by W. There is a constant risk of an acute event (such as a chest infection) that could lead to death due to the TEP, with the result that Z would succumb to whatever the acute event may be. Z could, in those circumstances, die very quickly or over a more prolonged period of time, with possible challenges in managing his clinical care. Dr H was taken to the references in the papers of Z's previous infections and the references to granulation in his PEG, all of which demonstrate the ever present risks of an acute event.

64. The benefit of continuing CANH for Z is that it would keep him alive, which is a very significant factor to weigh in the balance. Although stated simply it nevertheless is a very important consideration.

65. However, there are burdens Z's position carries. He currently receives CANH through his PEG. That has not caused Z any significant issues due to the skilled clinical care, at some stage it will need to be replaced and that can only be done at an acute hospital, with consequent risks of complications for Z. As Dr H observed *'It takes a lot to keep PEG working well'.* Dr H described the burdens of Z's feeding which

> causes him to be sick, whilst that has been managed by medication he is still sick at night despite the clinical efforts to manage that. As regards management of his tracheostomy, he requires suctioning on average 6 times a day, but it can be as much as 12 or 13 times, and lasts between 5 – 10 minutes. It is a wholly unpleasant procedure which causes Z to grimace and show other physiological signs of pain, not at a conscious level but he is experiencing it and having a reflexive response. There are the additional burdens of the tracheostomy needing to be changed each month. This Dr H describes as a highly skilled procedure due to the significant level of risk involved when the tracheostomy is taken out, even if only for a short period.

66. Z has been assessed as being in a prolonged disorder of consciousness ('PDOC'), more specifically a vegetative state of a chronic nature. No further assessments are sought or required. It is, in my judgment, a bleak reality for Z. The evidence is united that that position is not going to change; there is no recovery.

67. If CANH is not discontinued there are varying estimates as to Z's life expectancy, in the absence of an acute event. This could be at least 2 years and could be up to 7 years. More generally, Dr H considered that Z's position is likely to deteriorate due to age, which can increase the clinical burdens and risks for Z.

68. Due to the courage and dignity of those close to Z, his clinical team and the court have been given a valuable insight into Z's life prior to his diagnosis. This includes a rich description of his character and personality. Each of them have tried as best as they can to give their understanding of Z's wishes and feelings, his values and beliefs and how they may impact his attitude to his current predicament and to the continuation of treatment. Z's devotion to W is not in doubt, neither is her devotion to Z. Over the last 33 months she has visited nearly every day and fully involves herself in supporting Z's care. Whilst Z has understandably found the process of the meetings about Z's best interest decisions deeply distressing she has worked closely with the clinical team and they have a mutual respect for each other for all that they do together to help support Z. Such collaboration has the admiration of the court.

69. The picture that has been painted of Z is of someone who cared deeply for others, was an active and adventurous person who lived life to the full, loved to be outside and had found true happiness when he met, fell in love and married W. They were making exciting plans about the next stage of their life together which have been so cruelly cut short and taken away from them. Everyone close to Z agree that he would not want to live as he does now and would probably not want his friends, family and especially W to be burdened with the difficult decisions they have been asked to consider about his future care.

70. As Mr Patel observed when the time comes for us all everyone would want what W says Z would want; a quick and dignified death. That is not an option in this case. What I have to do is look at the wide canvas of evidence and consider what is in Z's best interests as between the available options.

71. It is with profound sadness, that I have reached the conclusion that Z's best interests are met by granting the application for a declaration that CANH is discontinued. I have reached that decision for the following reasons:

    (1) In balancing the burdens and benefits I have carefully factored in the benefit of the strong presumption of prolonging life but that can't be looked at in isolation, it has to be weighed together with the other considerations. I have also considered what may be termed as a benefit, which is the hope that Z would die quickly through some other cause, such as a cardiac arrest. Whilst that is a consideration, the reality of the medical evidence is that this is not more than a hope if CANH is continued. Even if such an event does take place, it may and probably will involve other complications.

    (2) The clinical and expert evidence speak with one voice, which I accept, that Z is in a PDOC and is in a PVS. There is no prospect of any recovery, his position has not materially changed for the last 33 months.

(3) The burdens of that condition are significant as the evidence has demonstrated, and could not be further from the independent, adventurous life Z lived before. That contrast is brought into sharp focus by the evidence that Z is wholly reliant on others for every aspect of his care and life; the complete antithesis of his previous life.

(4) The burdens of Z's treatment are also significant and are unlikely to get any easier with the passage of time. Z will become increasingly at risk of an acute event, which will be wholly unpredictable as to its timing, what the consequences for Z would be and for his clinical team to manage with consequent disruption and the risk of further medical intervention for Z. Although Z has no conscious experience of pain there is evidence of Z responding to certain care with grimacing, coughing and going red (for example during suctioning). In addition, there will be the need to replace the PEG, which will involve Z going to an acute hospital. This needs to be considered in the context that Z has not left the RHN since his arrival there in December 2021.

(5) If CANH is continued Z's life expectancy (subject to an acute event) is at least 2 years and could be up to 7. Dr H, who has had the most clinical involvement with Z, estimates between 5 – 7 years.

(6) If CANH is discontinued Z is likely to die within 1 – 3 weeks. Dr H considers it more likely to be a week. Dr Barry cautions that whilst these are the averages it can (unusually) be longer.

(7) What W understandably wants is for Z to be able to die swiftly and she believes that is what Z would want. That is not an option open to the court.

(8) The united view of the medical evidence is that it is in Z's best interests if CANH is discontinued. They are all experienced specialist clinicians who have taken great care in reaching their decisions. Whilst their conclusions are not decisive they have, in my judgment, carefully balanced the benefits/burdens in reaching their respective conclusions.

(9) In seeking to understand Z's wishes and feelings, beliefs and values there is unanimity that he would not want to live in his current condition. I agree. There are then differing views about what his wishes would be if he could not die swiftly. No one suggests Z had this discussion with them. W relies on the fact that

he searched dying with dignity after his diagnosis. What W says is that Z would find it difficult to accept the changes to his body brought about if CANH was discontinued. Even accepting that some changes may take place it has to be balanced with the alternative which is for him to remain living, possibly for a number of years, in a way that everyone accepts he would not want. As Dr H described he did not believe that Z would wish to be *'remaining alive at all costs in a state of permanent unconsciousness from which all semblance of a treasured identity has since departed'*.

(10) There would undoubtedly be a short term burden to CANH being discontinued asit may involve changes to be managed (such as thickening secretions requiring suctioning), changes in Z's appearance which may be very distressing to others but they would be relatively limited when compared to the longer term clinical management and risks if CANH remained in place. The PCP provides a well

thought out, proactive and flexible plan to manage Z's condition so that he would experience minimum interference. Whilst I recognise the distress this decision will cause to W and others, in my judgment, when balancing the benefits/burdens of the alternatives it is the option more focussed on Z's best interests which is what guides any decision I reach. Based on the evidence the court has Z would not want anything to cause W distress but equally he would be concerned about the continuing conflict, the position he is in and there being no other better option for anyone.

(11) I fully recognise that there can be no guarantee about any of the timescales given,and that factor has to be weighed in the balance. However, the collective experience and expertise of Drs H, Nair and Barry, which I accept, was that if CANH was discontinued it is likely Z would die within 1 – 3 weeks.

(12)In my judgment, the evidence demonstrates from those who have actual experience of this that discontinuing CANH will enable Z to die with dignity, in the least discomfort, in the greatest peace and with those who want to be with him to be able to do so.