



Neutral Citation Number: [2024] EWCOP 31 (T3)

Case No: 14034582

IN THE COURT OF PROTECTION
IN THE MENTAL CAPACITY ACT 2005

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 23 May 2024

Before :

MR JUSTICE CUSWORTH

Between :

NHS North Central London Integrated Care Board

Applicant

- and -

(1) PC

Respondents

(By her litigation friend, The Official Solicitor)

(2) MC

(3) The Royal Hospital for Neuro-Disability

Rhys Hadden (instructed by **Hill Dickinson LLP**) for the **Applicant**
Claire Watson KC (instructed by **The Official Solicitor**) for the **First Respondent**
David Lawson (instructed by **GN Law**) for the **Second Respondent**
Katie Scott (instructed by **Bevan Brittan LLP**) for the **Third Respondent**

Hearing dates: 24 – 26 April 2024 and 23 May 2024

JUDGMENT

This judgment was handed down in court at 2pm on 23 May 2024 and by release to The National Archives on 7 June 2024.

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This judgment was delivered in public but a transparency order is in force. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained within the judgment) in any published version of the judgment the anonymity of the parties must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Cusworth:

1. This application arises from a truly tragic situation. PC was born on 11 March 1989 in Turkey and moved to the UK in about September 1993. Her parents separated when PC was 6 and after that she lived with her mother, MC, and her sister. She has half-siblings on her father's side of the family. There was a period of estrangement from them, until the death of a close relative in 2014 when they began to see each other. After leaving school PC studied and worked. By 2020, PC had decided to return to university with a view to a change in her career. She was careful with her health, enjoying exercise, walking and healthy eating. She is described by her mother as having been "full of life".

2. On 28 July 2020, when she was aged just 31, PC suffered a cardiorespiratory arrest and collapsed at home. A lack of cardiac output for about 30 minutes led to her brain being deprived of oxygen, which caused a severe hypoxic ischaemic injury. She has been left in what has been assessed as a Prolonged Disorder of Consciousness ('PDOC'), at the low end of the spectrum of awareness: her condition is described as a Minimally Conscious State minus (MCS-). She is now aged 35. She is cared for at the Royal Hospital for Neuro-Disability ('RHN'), which has been joined as a party to these proceedings. Her placement there is commissioned by the NHS North Central London Integrated Care Board ('the ICB') who is the applicant in the proceedings. The other parties are PC's mother, MC, and PC herself, through her litigation friend, the Official Solicitor.

3. The ICB made its application to the Court of Protection on 2 February 2024, seeking determinations under the Mental Capacity Act 2005 ('MCA 2005'). They seek a declaration that PC lacks capacity to conduct these proceedings, and to make decisions regarding her medical care and treatment (s.15(1)(a) MCA 2005); and further that it is not lawful, and not in her best interests, to continue to receive the life-sustaining clinically assisted nutrition and hydration ('CANH') that she is currently relying on from RHN (s.15(1)(c)). They seek an order under s.16(1)(a)/(2)(a), and s.17(1)(d) of the MCA 2005 that it would be in her best interests to refuse to consent to the continuation of CANH and other life-saving treatment, and to consent to palliative care only.

4. PC was first admitted to the RHN on 14 October 2020. She was transferred to a specialist nursing home, which is part of the RHN where she remains, on 15 March 2021. The process of making a best interests decision about her CANH was initiated on 8 March 2023, and the case was then referred to the ICB on 10 July 2023. I shall not in this judgment deal with the question of the time that this matter has taken to come before the court, about which separate evidence has been filed, but which has not been the subject of dedicated submissions before me. My focus in this judgment is solely an assessment of PC's best interests.

5. This matter initially came before me for determination for 2½ days from 25 March 2024, but at that stage, only the ICB and the Official Solicitor had party status and were represented. PC's mother had not been joined as a party, and had only recently been served with the papers in the case. She indicated to me that she wished to become a party and have the opportunity to address the court. She does not speak English well, but wished to oppose the declarations being sought. I therefore made an order joining her. I also joined the RHN, in circumstances where the questions of timing and decision making in PC's case appeared to remain live. Although adjournment was opposed by the ICB and by the Official Solicitor, I granted a short adjournment of just under 1 month, and the matter has come back before me for determination over 3 days from 24 April 2024.

6. I have been enormously assisted by the written and oral submissions from Counsel for all four parties, and I note especially that Mr Lawson for PC's mother, MC, initially took on her representation on a pro bono basis before the eventual grant of legal aid. This is a difficult and finely balanced case, which has been dealt with in a sensitive but focussed way by all involved.

The Law

7. I have been greatly indebted to counsel for the ICB, Mr Hadden, and for the Official Solicitor, Ms Watson KC, for producing before the 25 March hearing an 'Agreed Summary of Legal Principles', and with which Counsel for the two other parties at this hearing both agree. What follows in this section is based upon that document.

8. 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 designed to help decision-makers navigate the troubled waters of end-of-life decision making.

a. First, in relation to the provision of clinically assisted nutrition and hydration (“CANH”), it has been long-established that this amounts to medical treatment (as opposed to a facet of basic care).

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

c. Third, Lady Black noted the importance of professional guidance in this context.

d. Finally, at [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.’*

9. In the context of this case, while there is no difference of medical opinion, there is a lack of agreement from some members of PC’s family in respect of the proposal to withdraw CANH, and questions raised by PC’s mother about whether there has been sufficient assessment for a final determination to be made. In light of this, an application to the Court of Protection is necessary to achieve a determination under the MCA 2005.

10. Sections 1 to 3 of the MCA 2005 set out the principles by reference to which capacity of those over the age of 16 is to be determined. Sections 1-3 MCA 2005 are not set out in full below as capacity is not a disputed issue in this case:

“1 The principles...

(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

[...]

2 People who lack capacity

(1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain..."

[...]

3 Inability to make decisions

(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,*
- (b) to retain that information,*
- (c) to use or weigh that information as part of the process of making the decision, or*
- (d) to communicate his decision (whether by talking, using sign language or any other means).*

11. Capacity is as explained not a contentious issue in this case. The evidence that PC lacks capacity to conduct these proceedings and make decisions about her treatment is incontrovertible, and is accepted by all parties. The presumption of capacity contained in s.1(2) of the MCA 2005 is displaced and, therefore, decisions about continued treatment for PC have to be made on her behalf. I am invited to make declarations under s.15(1)(b) MCA 2005 accordingly.

12. **Best interests.** Where a person is unable to decide for herself, there is an obligation to act in their best interests: s.1(5) MCA 2005. The statutory best interests “checklist” under s.4 MCA 2005 provides:

(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).

13. PC has not made any 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 PC's behalf in relation to a matter or matters concerning her personal welfare,

including giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for her. 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.

14. The question which the court should therefore ask itself is whether it is in PC's best interests to continue with CANH. As Baroness Hale explained in *Aintree v James* [2013] UKSC 67:

"[22] ...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..."

[35] The authorities are all agreed that the starting point is a strong presumption that it is in a person's best interests to stay alive...Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.

*[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)...*

"[39] ...in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

15. At [45] in the same case, Baroness Hale made clear that the purpose of the best interests test is to consider matters from the patient's point of view. She continued:

“That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament... 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.”

16. Where a patient is suffering from an incurable disability, the question is whether she would regard her future life as worthwhile. The quality of life should not be judged by the values of others but from the particular perspective of the patient: the judge must arrive at an objective assessment of whether continuation of life-sustaining treatment is in this patient's best interests, seen through the “*prism of the subjective position of the patient*” (*Barnsley Hospital NHSFT v MSP* [2020] EWCOP 26 at [33]).

17. As was made clear in *Re J* [1991] Fam 33, it is not for others to say that a life which a patient would regard as worthwhile is not worth living. Likewise, dignity in life and death is a difficult subject which is not readily susceptible to objective definition. What one woman with her own subjective values and beliefs regards as undignified may not be regarded as so by another with a different set of values and beliefs. Thus, an intense focus on the patient concerned and understanding how they would likely view the situation is important rather than the imposition of a societal or cultural norm.

18. The fundamental starting point is a strong presumption that it is in a person's best interests to stay alive. As Sir Thomas Bingham MR said in the Court of Appeal in *Airedale NHS Trust v Bland* [1993] AC 789 at [808], “*A profound respect for the sanctity of human life is embedded in our law and our moral philosophy*”. In the

context of the MCA 2005, the principle of the right to life can be “*simply stated but of the most profound importance. It needs no further elucidation. It carries very great weight in any balancing exercise*” (*W v M* [2011] EWHC 2443 (Fam), Baker J at [222]).

19. Munby J (as he then was) stated in *R (Burke) v GMC* [2004] EWHC 1879 (Admin) at [116], (approved by the Court of Appeal [2005] EWCA Civ 1003 at [61]),

“There is a very strong presumption in favour of taking all steps which will prolong life, and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In case of doubt, that doubt falls to be resolved in favour of the preservation of life. But the obligation is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity...”

20. The sanctity of life is not however absolute. There are cases where it will not be in a person’s best interests to receive life-sustaining treatment: *Aintree v James* at [35] (above). As Lord Goff said in *Bland* at [864], “...*there is no absolute right that a patient's life must be prolonged by treatment or care, regardless of the circumstances.*”

21. Chapter 5 of the **MCA 2005 Code of Practice** (‘the Code’) issued under s.42 MCA 2005, titled ‘How should someone’s best interests be worked out when making decisions about life-sustaining treatment?’ includes the following guidance, of which the court must take account:

“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...

5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests...

5.38. In setting out the requirements for working out a person's 'best interests', section 4 of 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)."

22. Hayden J considered the weight to be given to the wishes and feelings of an incapable adult in the best interest assessment in *M v N* [2015] EWCOP 76:

"[28]...where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's 'best interests'. Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them. Finally, I would observe that an assessment of P's wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed non-

verbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P's views from what he may have done in the past in circumstances which may cast light on the strength of his views on the contemplated treatment... recent case law... has emphasised the importance of giving proper weight to P's wishes, feelings, beliefs and values...

The Code of Practice

[29] Section 42 MCA requires the Lord Chancellor to prepare a Code of Practice. Every decision maker, including the court, has a statutory duty to "have regard" to the Code of Practice: see section 42(5) MCA. Paragraph 5.31 of the Code is of particular relevance...

[30] It is clear, therefore, that the framework of the Act and the scheme of the Code of Practice place great emphasis on the importance of personal autonomy and the obligation to be alert to direct or indirect discrimination against those who lack capacity. Decisions taken in the 'best interests' of an incapacitous individual must factor in the recognition that respect for an individual's past and present (where relevant) wishes and identifiable codes and beliefs by which he has lived are a crucial part of promoting best interests. To subvert these to a substitution of an objective evaluation i.e. to superimpose what the Court thinks best, may result in indirect discrimination. The central objective is to avoid a paternalistic approach and to ensure that the incapacitous achieve equality with the capacitous."

23. The court also has a duty to consider the views of anyone engaged in caring for the patient or interested in their welfare (s.4(7)(b) MCA 2005). This duty will incorporate the views of professionals and the views of family members or close friends, where such views exist. The role of the family can also be important in providing the court with relevant information about the patient's pre-morbid character, beliefs and values and relevant expressions of wishes about attitudes towards being given intrusive life-preserving treatment in the face of severe disability.
24. With regards to the extent of the investigative process to be undertaken prior to a best interests decision being made, it was said by Peter Jackson LJ in *Re M (Incapacitated Person: Withdrawal of Treatment)* [2017] EWCOP 19 at [27] that:

"...in reaching this decision, I was mindful that this was in effect an application made by agreement and that there are always more investigations

that can be made, questions that can be asked, stones that can be turned. Here, I was satisfied that the court had all the essential information and that further inquiries would not alter the fundamentals ... and that 'what is important is that those called upon to express a view should do so conscientiously, drawing upon their personal and professional knowledge of the individual concerned'.

25. The courts now place less emphasis on establishing a specific diagnosis of Permanent Vegetative State (“PVS”) or MCS but will nevertheless require evidence that it is not in the patient’s best interests to continue life-sustaining treatment and that there is no prospect of meaningful recovery. Clinical evaluation and diagnostic testing (e.g. such as Wessex Head Injury Matrix (‘WHIM’), the Coma Recovery Scale-Revised (‘CRS-R’) or Sensory Modality Assessment and Rehabilitation Technique assessment (‘SMART’)) remain an important evidential aspect in such cases.
26. Whether or not a person has the capacity to make decisions for herself, they are entitled to the protection of the European Convention on Human Rights (“ECHR”). In the present context, the relevant rights are found in Art. 2 ECHR (the right to life), Art. 3 ECHR (protection from inhuman or degrading treatment) and Art. 8 ECHR (the right to respect for a private and family life). I have also been referred to the current versions of the key clinical guidance, which are: (a) Royal College of Physicians – *Prolonged Disorders of Consciousness following sudden onset brain injury: National Clinical Guidelines* (March 2020), and (b) Joint Guidance published by the BMA, RCP and GMC – *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales* (2018) – although in the case of the latter document not during submissions in court.
27. Mr Lawson for MC understandably places emphasis on the decision of Jonathan Baker J as he then was, in *W v. M* [2011] EWHC 2443, where he acknowledged the possibility of withdrawing treatment from people in MCS and applied a balance sheet analysis when deciding not to do so. Having recorded that Counsel for the Applicant in that case had submitted that the "*broad thrust of the evidence is that at best M's dominant experience may be one of contentment*", and that the absence of pain, distress or discomfort is not in itself a positive feature, he said:

“235. Able-bodied people frequently feel (even if they do not say so) that disability invariably restricts the enjoyment of life. With the growth in understanding about disability in recent years, however, has come an awareness that people with disability often experience profound enjoyment of life, within the limitations that their disability may impose... On one view, the pleasures of life in such circumstances may appear smaller, but that does not mean they can be disregarded. I do not accept the submission that the absence of pain or discomfort is not in itself a positive feature of life. Comfort and contentment can be, in my view, profoundly positive sensations...”

236. The contrast may be more stark where a previously healthy and active person such as M is laid low by illness and becomes severely disabled. Because M is no longer able to enjoy life in the way that she was, it is wholly understandable that members of the family think that she does not enjoy life at all. Having considered the evidence of the carers, however, I find that M does enjoy some aspects of her life. I do not accept that her experiences are wholly, or even on balance, negative....

237. In short, I do not find that her current life is overwhelmingly negative, or "overly burdensome" in the words of paragraph 5.31 of the Code of Practice, or that there is no prospect of any improvement in the quality and enjoyment of her life.”

28. Jonathan Baker J also emphasised the respect that had to be given to the dignity and value of life with disability (notwithstanding the remote prospects of recovery). Counsel for the Applicant in that case had suggested that M’s dignity would be promoted by the withdrawal of CANH, but the Judge responded thus:

“241. Anyone would wish the end of life to be as dignified as possible. In my judgment, however, there is dignity in the life of a disabled person who is being well cared for and being kept as comfortable and as free from pain as possible, and being provided with the maximum opportunity to extend their enjoyment of life that their disability allows.”

29. The judge recorded the advantages of continuing CANH in that case, at [248], as including the preservation of life for perhaps another 10 years, and that M would be spared the effects of withdrawing CANH. He found that: *“Even with medication and high quality care, there is a significant risk that the process of dying by starvation and dehydration will cause her pain and distress”*. However, he went on to add that, in addition to experiencing life as a sensate being, she would continue to gain pleasure from things such as company, listening to conversation, music and sensory experience, and that it was likely that her enjoyment of life could be extended by the introduction of a planned programme of stimulating experience. He also found that

pleasure could be added to her life by making her room more comfortable and homely. The balance in that case fell with the importance of preserving life.

30. Care however should be taken with an overly simplistic application of the balance sheet approach. Some factors, such as the sanctity of life, will always be of the utmost importance in any case, whereas other factors may be of greater or lesser significance in any particular set of circumstances. It is never therefore simply a case of adding up the numbers of factors in each column – a far more holistic consideration is called for – ‘*all the relevant circumstances*’ as mandated by s.4(2) of the MCA 2005.

The Evidence

31. In this case (leaving aside those whose evidence goes only to timing) I have considered three statements from Dr A, one of PC’s clinicians, who is a GP providing a GP service to the RHN, and heard her give evidence to me by video link. I have also read statements from Dr B (a consultant in Neurorehabilitation at the RHN), who initially treated PC, and from Ms B, who is a Matron at the RHN. I have read two reports from Professor Derick Wade, also a consultant in Neurological Rehabilitation, who provided the second opinion in this case, and also gave live evidence to me. I have also considered a number of other articles and papers which he has prepared during his career in the course of his cross-examination.

32. I have also heard live evidence from 4 members of PC’s family: her cousin, MK; her mother, MC; her father, AO; and her half-sister, SO. I have watched two short videos of PC at the RHN provided to me on MC’s behalf.

Medical Evidence

33. Ms B in her statement records that PC is unable to communicate her needs in any way, but can sometimes display behaviours which could be perceived as distress. During the meeting of her daily personal care needs, and on occasion without identified triggers, she appears uncomfortable with facial grimacing, moaning and groaning. The staff are unable to see any signs of positive emotions or expressions, and perceive her to be suffering at times. When not showing discomfort, however, she displays as settled and calm.

34. Dr A describes that PC has not regained any meaningful level of function, but that she can at times appear uncomfortable from spasms or for no identifiable reason. She occasionally suffers infections related to her severe neuro-disability, which are distressing and can be accompanied by seizures. Dr A also provided evidence about the plans for palliative care in the event that CANH is discontinued. In her oral evidence she explained that although PC's seizures are controlled by medication, she does need occasional suctioning to prevent choking and deal with secretions, and is often found to be crying. She has been treated with morphine and anti-depressants, which have helped to relieve her distress, but the crying still occurs. Dr A described some minimal awareness and the possibility of pain. None of the caring staff have detected pleasure or other positive behaviours.

35. I accept and adopt the following summary of PC's current condition, which is taken from the final position statement filed on her behalf by Ms Watson KC for the Official Solicitor:

- a. PC has suffered a global hypoxic brain injury which affects all parts of her brain;
- b. PC is in PDOC and has been assessed to be at the lower end of the spectrum of awareness (MCS-);
- c. PC is able to breathe independently but is unable to eat or drink and can therefore only receive nutrition and hydration by way of CANH;
- d. She is immobile and unable to communicate her needs in any way;
- e. She is also doubly incontinent and requires 24 hour nursing care which includes personal care such as washing, dressing and changing her continence pad.
- f. As a consequence of her brain injury, PC has developed contractures and suffers from spasms, which will not improve and are likely to worsen over time;
- g. PC has a history of chest infections, infection of the skin and urinary tract infections. As a consequence of her immobility and inability to manage secretions and the need for a PEG and suprapubic catheter, PC remains at risk of developing infections in the future;

- h. PC displays pain behaviours characterised by facial grimacing, moaning and crying;
 - i. PC's condition may fluctuate from day to day but there will be no sustained improvement in her clinical state.

- 36. Professor Wade's first report was dated 17 May 2023. At that time it was understood that PC's family supported the decision to discontinue CANH. He recorded that it was by then nearly 3 years since the original episode of hypoxic brain damage, with no detectable change, whereas almost all recovery occurs within 12 weeks. He opines that PC will never have any autonomy or control, be able to undertake any functional activity or participate in helping a carer, or to communicate or interact socially. He was satisfied then that the conclusion from a best interests meeting held on 13 April 2023 – that it was in PC's best interests not to continue the treatment – was the right one, and he recorded that he had come to the same conclusion.

- 37. However, it later became apparent that PC's family were not entirely clear about the situation. In her statement dated 19 April 2024, MC, who speaks little English and gave evidence to me through an interpreter, explains that she did not fully understand the purpose of the first meeting on 14 March 2023, but that by a later meeting on 6 June, and having considered the matter with PC's cousin, MK, she was clear that she did not want CANH to be withdrawn. She said that she was not aware of a letter written earlier by SO, PC's half-sister, confirming the family's decision to agree to discontinue the treatment. Accepting the genuineness of the currently held views of MC, MK and AO, no questions were put to them about their earlier position. SO stands by the content of the letter which she wrote, and confirmed her position in oral evidence.

- 38. Professor Wade therefore produced a second report dated 7 March 2024, in which he reconfirmed his original view. Over a further 10 months there had been no substantial or consistent observations to suggest any significant level of awareness – he concluded that PC is unaware of herself or her environment. He considered the prospect of any improvement in her condition 'non-existent', and explained that references by Dr A to PC being 'alert' meant no more than that her eyes were open.

There would be no significant sustained improvement in her clinical state affecting her autonomy, ability to function or communicate, social interaction or need for care or institutional living. Her increasing spasticity would only worsen, and would not get better. He determined that the views now expressed by the majority of the family could not be determinative, and contrasted them with the different views which had been understood as expressed by the family at the original meeting in March 2023.

39. Professor Wade went on in the report to set out the reasons for his newly reconsidered determination, but many of these were based upon the words of the family as recorded in March 2023, and now disavowed by a number of them. I consider that any attempt to place an interpretation on those words now, either positive or negative, is unsafe, given the position being articulated by MC and supported by others in her family, that she did not then fully understand the purpose of the meeting. It is clear that both of PC's parents now are very firmly opposed to the cessation of CANH, and I accept that that is their genuine position at this time. I will discuss the picture that I have of PC before her cardiac arrest, which of course largely derives from the family's account, below.
40. Professor Wade also discussed PC's experience of pain, concluding that if she has experience at any level, it will be predominantly one of pain and distress. He noted reports of some increase in behaviours associated with pain, sufficient to distress treating nurses. He also noted that increasing a morphine-based medication for her seemed to lessen the pain behaviours. He considered the challenge of balancing increased sedation against apparent pain and distress. He suggested that because pain is arguably a more basic phenomenon than consciousness, the pain matrix may be more resistant to degradation. He concluded that the possibility that PC is conscious of pain was unlikely, but should not be discounted.
41. He evidently continued to consider this conclusion, and on 10 April 2024, 2 weeks before this hearing, he produced and circulated a paper, entitled 'Pain in patients with a prolonged disorder of consciousness', prompted by this case, but intended

ultimately (he told me) for wider discussion. Here he came to a more developed conclusion. He wrote:

“We have no convincing evidence that an unconscious person cannot experience pain. We have plausible, if not compelling, reasons for thinking that, at some fundamental level, they might experience pain. A person, not a brain, feels pain, and the absence of the brain networks or their activation cannot prove the absence of pain. Although they may not remember past pain or anticipate future pain, this does not reduce the suffering at the time.

This conclusion has three crucial consequences when managing anyone with a prolonged disorder of consciousness:

- *We should continue the policy of treating people who exhibit pain behaviours in ways to minimise and control pain, for example, giving prophylactic analgesia or anaesthesia and analgesics when pain is apparent,*
- *We should manage people in ways that minimise the likelihood of pain,*
- *When considering what is in a person’s best interest, the likelihood that they have experienced and will continue to experience some pain should be a relevant, probably vital factor.”*

42. Cross-examined by Mr Lawson for MC, Professor Wade acknowledged that the document was precipitated by these proceedings. He described still making up his mind about the experiencing of pain when minimally conscious – he expected that there was some sensation, but couldn’t gauge its extent. He also accepted that if able to experience pain, PC would also be capable of experiencing pleasure.

43. However, the collected evidence does not indicate that this has been happening. Ms Watson KC provided the following summary of the evidence in this area, which I accept and adopt:

- a. Reports by the nursing team that PC appears uncomfortable with facial grimacing, moaning and groaning during her daily personal care and when opening her bowels;
- b. Professor Wade’s evidence that *“the most important change in her condition is the emergence of more pain behaviours”*;
- c. Ms Earnshaw’s attendance note of her visit to PC on 7 March 2024 during which it was reported by Nurse Ms D that PC is in distress and pain now and there have been more episodes of her crying and moaning recently; and the

OT, Ms C, that PC always seems uncomfortable and when the OT team try to stretch her she grimaces and cries;

- d. The evidence of a reduction in pain behaviours in response to an increase in medication, including the cessation of crying overnight on starting anti-depressant medication;
- e. MC's evidence that PC often cries when visited by her and other family members and when she visits PC "*she looks at me with sad eyes...I know her expression better than anyone and I believe this is because PC recognises me and feel bad.*";
- f. The absence of any evidence that PC has displayed behaviours objectively associated with pleasure or comfort since 2020, when it was recorded on the CRS-R that she "*demonstrated ability to smile/stick tongue out to verbal command, but this was not always reproducible or consistent.*"

44. What was clear from Professor Wade's evidence is that a person's ability to feel pain is only likely to increase with any increased level of consciousness, but that also with the capacity to feel pain or discomfort may come some ability to experience comfort, if not pleasure; which experience, as Jonathan Baker J made clear in *W v M*, must be counted as a positive, if identified. It is striking, however, that no evidence of any such experience has been identified here, even by PC's family. MK said that she could '*see in PC's eyes that she will want to continue living*', rather than that she looked content with her situation. MC herself records that MK has been too upset by the latter's presentation to visit PC very much recently. She also records as set out above PC looking at her with '*sad eyes*', and before a recent increase in medication, as crying a lot, perhaps because she was in pain or was sad.

45. Professor Wade also denied that there was any serious prospect of misdiagnosis in this case, and explained that previous statistics which suggested high rates of misdiagnosis were explained by the hard lines between levels of consciousness that were previously drawn before the best interests test was adopted. Asked whether the evaluations of PC that had been carried out were inadequate, he commented that the initial 2020 assessments had been appropriately thorough, and that subsequent assessments need only confirm that there had been no discernible shift in her condition. He rejected any

suggestion that the assessments carried out had been inadequate, and pointed out that whilst more intensive tests were appropriate in the early stages after a brain injury, these were no longer required 4 years after the injury has been sustained. He commented that recommendations in papers from the United States had to be seen in the context of a much quicker likely assessment of condition being carried out in that jurisdiction. And further that recovery after traumatic brain injury was much more often seen than after a hypoxic injury such as that suffered by PC.

The Family

46. MC, PC's mother, has filed a written statement, and I heard from her in evidence, although very understandably she soon became upset and left the witness box. She was however very clear that she did not wish for CANH to be discontinued, and in her statement told me about PC as a person. She described her as ambitious, working first before planning to return to university for a second degree. She was careful with her health, looked after her diet, and enjoyed travel. She had always been full of life, and was a brave woman. She had lived at home throughout her life, but had never talked about disability or death with her mother. She describes visiting PC now several times each week at the RHN, which I accept, although the visits registered and reported by Ms B are significantly fewer. It may be that she does not always sign in when she visits.

47. As explained, she challenges the professionals' account of the early best interest meeting on 14 March 2023, so I will not put weight on what has been reported of that meeting. Likewise, the letter which purports to come from PC's family dated 6 April 2023, and which reluctantly accepts that discontinuation of CANH is in PC's best interests, is not now accepted as being MC's position then, so I will treat it only as being the views of SO, whose name is at the foot of the letter. By a later letter dated 6 June 2023, both of PC's parents described themselves as either not mentally stable (the mother), or not in a stable mindset (the father), at the time of the initial meeting.

48. I then also heard from MK , who is PC's maternal cousin, and who had written a letter to the court dated 8 March 2024, in which she described their closeness and spoke of

PC as a cheerful character who enjoyed the little things in life. She gave importance to education and always wanted to improve herself. MK feels that PC will want to continue living and will feel hope. She said that ‘one day, her body mind and soul will be free from this trauma’. She described PC as funny, lively and enthusiastic, and asked the court to look at who she was before she collapsed. MK, too, became very upset when giving oral evidence.

49. AO, PC’s father, also made clear to me in his evidence that he opposed the discontinuation of CANH, describing her in his letter of 6 June 2023 as ‘our joint beacon of light.’

50. SO is PC’s half-sister. In her brief evidence to the court she confirmed that she stood by her previously expressed views, which differ from the position now adopted by those others who gave evidence to me. She therefore holds to the content of the letter which had been sent to the court on 6 April 2023. There she had written:

“Before PC suffered the cardiac arrest, she was looking forward to starting university to do a biomedical science course she had applied for after [working] for over 5 years. PC was an caring individual who would go above and beyond for her family and friends. Her hobbies were drawing picture, going to the gym, listening to music and spending time with her siblings and nephew...if PC could see herself now she would not want to be in the situation she is in at such a young age, As we know there is nothing we can do to take away her pain in such a difficult time. She was always caring and considerate and a healthy person and would not want to carry on like this.”

Adjournment

51. At the conclusion of the medical evidence, Mr Lawson sought to adjourn the application on the basis that further assessment of PC was required before the court could be satisfied of her condition. As I explained at the time, in rejecting that application, I was satisfied that there was no genuine uncertainty in PC’s diagnosis, which had been properly and effectively carried out soon after her cardiac arrest in 2020; and subsequent less intense testing since had served to confirm that there had been no appreciable positive change in her position.

52. The only element of medical uncertainty was, as explained, the question of whether PC was capable of experiencing the pain and discomfort which her outward expressions seem to manifest with some regularity, and which expressions then respond to treatment with morphine or anti-depressants. No amount of further assessment would serve to answer that question, and such assessment would therefore have served no useful purpose. Further, there was no evidence available or suggested which indicated any real prospect that PC may be functioning at a higher level than all of the previous assessments had indicated. Another series of assessments was not therefore necessary, as all of the medical witnesses agreed. Professor Wade went as far as to express the view that it would be a 'waste of time'.

Evaluation

53. So, I come to consider the specific elements in s.4 of the MCA 2005. Firstly, and sadly, it is very clear that there is no prospect that PC will ever herself have capacity in relation to this decision, nor can she participate in the decision-making process in any meaningful way. The quality of PC's care has been uniformly praised by her family. No-one involved with her, and certainly not this court, is motivated by a desire to bring about her death.

54. What then of her wishes and feelings, beliefs and values? Given her young age, it is not surprising that PC had not had any meaningful conversations with her friends or family about her attitudes to the continuation of life in the sad situation in which she now finds herself. This is not a case where any element of powerfully held religious belief has to be taken into account.

55. Her family make it clear that PC was a strong hopeful person, and a fighter. That of course may cut both ways, for here there is no real hope of recovery. She was evidently a thoughtful and ambitious person, who envisaged (as many of her age would) a long and healthy life. Her family's very understandable reason for hope is that she might find a way to recover; but the evidence is that such an outcome is not even a remote prospect. I have little evidence which might help me interpret how PC might have felt had she known what would befall her, aside from SO's letter. I take

that into account, but only alongside the views also expressed to me by MC, MK and AO. In the absence of a clear steer from her family about her own likely position, I have to consider the other factors in light of what I do know of her personality.

56. What then of other factors that PC would be likely to consider, were she able to do so? I have no doubt that she would be concerned at her family's upset and suffering at her condition, and would want to avoid that for them if she could. She had lived with her mother for all of her life before her illness, and would want to do all that she could to protect her. I have no doubt that she would be very concerned about her mother's reaction to her death. Equally too, I have no doubt that she would be greatly distressed by the evident turmoil afflicting both her mother and her cousin MK. I'm sure that both her father and her sister SO are also suffering, which PC would wish to bring to an end. I'm sure too that other family members are equally distressed. Considering the competing arguments it is impossible to form a conclusive view about PC's likely attitude here – whether she would choose to remain in her current state, and so leave her family, desolate as they are, continuing to visit her perhaps for another decade; or whether to enable an ending now which might prove the start of a healing process, but having first brought to a head their building grief. I must conclude that she could form either view as to the best course for her family, so I am left to look primarily at her personal best interests.

57. I also have to take into account the views of PC's carers. Whilst the suggestion that PC's condition is actively deteriorating is not made out on the evidence, I accept that there is no prospect of any tangible improvement in her condition. It is striking that there have been no observations of any comfort or pleasure reactions in her, and that the staff at the RHN have been themselves upset by the distress that her daily life can cause her. Whilst her suffering can evidently be alleviated by increasing doses of morphine, or anti-depressants to control her night-time crying, this increasing sedation as a substitute for some remote consciousness afflicted by unknowable pain and discomfort appears to offer little upside for her. The prospect that there may be elements of consciousness left to her of course strikes deep with her family. However, it is unavoidable that there is simply no evidence that PC's experiences offer her any

positives. There is no evidence of any enjoyment of life. The only evidence is of her exhibiting discomfort and pain. This is therefore a very different case from *W v M*.

58. I do bear in mind that there is no need for PC to receive any especially burdensome treatments. It is however sad to note that just the everyday functions of caring for her are seen to cause her distress by the nursing staff, which distress is only partially masked by medication. I accept Mr Lawson's point that for much of the time in the medical notes, PC is recorded as being 'stable', but that appears for the most part to be stability generated by sedation, and not equivalent to any element of comfort.

59. I do not take any particular account of the dignity of PC's position, as I have no evidence by which to gauge her own attitude to such a concept, so I cannot be clear that there is any particular lack of dignity that she would perceive in her current circumstances. I agree with the observation of Jonathan Baker J in *W v M*, to the effect that there is dignity in being well cared for and being kept comfortable and free from pain. Sadly, there is little prospect for PC that this will afford her any opportunity to enjoy her life.

60. In the event that CANH were to continue for the foreseeable future, I must conclude that it would not bring with it for PC any real prospect of recovery, or any improvement in the quality of her life, which as Dr A says in her first statement "*cannot reasonably be considered a good quality*". The evidence is clear that any progression which she does experience going forward, nearly 4 years on from her initial brain injury, will be negative rather than positive. I nevertheless remind myself of the importance of sustaining life, even where there is little hope of recovery, and of the finality likely if treatment is withdrawn.

61. In the event that CANH is discontinued, Dr A has given evidence about the prospect of a transfer to a hospice closer to her family to deliver the palliative care that would then become appropriate. Prior to the withdrawal of CANH, there could first be a trip home for PC, although not to a property which she has visited before - so certain checks would have to be carried out first. Then, the clinical team at the RHN have

identified a hospice as a suitable facility, to which a transfer could be secured subject to space at the point when it is required. This move would be supported by the ICB as well as the RHN, if requested by PC's family. If not, then there is what Dr A describes as 'ample' provision for palliative care on site at the RHN. Whilst the discontinuance of CANH may of course itself lead to the prospect of some discomfort and pain, Dr A describes that this would be '*carefully managed with a robust terminal care plan, and active monitoring by care staff*'. I remind myself that the management of pain would appear to be the dominant feature of PC's life whilst CANH continues to be administered, as well.

Conclusion

62. In all of those above circumstances, I find that the principal advantage to PC of continuing with CANH would be the simple preservation of her life, which is of course a fundamental principle of the utmost importance. However, in trying to interpret the value to her of her current existence, I cannot avoid the conclusion that her life has not since 2020 and will not going forward be one that affords her any measurable degree of pleasure or even contentment. Further years of life may be of value to anyone, however disabled, if they are able to derive some positives from their existence. Very sadly, the only evidence that I have of PC's condition and mood, when not sufficiently regulated by medication, is of discomfort and the experience of pain. Those who care for her are clearly worried for her. Her family look to her reactions as signs of consciousness, but what they describe does not amount to more than the appearance of suffering. It is very clear to me from all that I have read and heard that the burden of her condition on PC is a heavy one.

63. Whilst I accept Mr Lawson's submission that the process of withdrawing CANH treatment may bring with it a degree of suffering for PC, it would be treated in the same way that her ongoing pain is being treated, and so would not in my view represent a disproportionate additional burden. Any additional pain will be ameliorated by medication and experienced end of life care, and be limited in time. There is no evidence that PC is deriving any positive experience from her current life to which she might ascribe value, or which might render more time in her current state as any sort of benefit for her. She will, if CANH is withdrawn, be freed from the pain

and discomfort which she is currently suffering in her day to day life, which are unlikely to lessen for her to any degree for as long as she remains alive. She will be spared the burden of living a life which does not obviously bring her anything other than pain. Her death will bring great sadness for her family, but it will be sadness not augmented by further years of her suffering before it arrives.

64. Factoring in objectively the medical evidence of her current condition and prognosis, and considering the views of her family, the opinions of all her treating team and the second opinion from Professor Wade, and bearing in mind all that I do know of her as a person before her injury, I agree with the Applicant ICB, with the RHN, and with the Official Solicitor, that for PC the benefits of continuing CANH are clearly outweighed by the significant burdens for her of her continuing condition. I am entirely satisfied from all that I have read and heard about PC that she would not wish to continue with life in her current condition. I am reluctantly satisfied that it is not in PC's best interests to continue to administer to her life-sustaining medical treatment in the form of CANH, but rather that, with great sadness, it is in her best interests to begin to implement for her a palliative care regime the consequence of which (but not the aim) will be the end of her life.
65. That is my judgment.