



Neutral Citation Number: [2024] EWCA Civ 895

Case No: CA 2024 001218

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM the Court of Protection sitting in the High Court
Mr Justice Cusworth
14034582

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 31/07/2024

Before:

LORD JUSTICE BEAN
LADY JUSTICE KING
and
LORD JUSTICE BAKER

RE: PC

David Lawson (instructed by **GN Law Solicitors**) for the **Appellant**
Rhys Hadden (instructed by **Hill Dickinson LLP**) for the **1st Respondent**
Claire Watson KC (instructed by **the Official Solicitor**) for the **2nd Respondent**

Hearing date: 18 July 2024

Approved Judgment

This judgment was handed down remotely at 11.00am on 31 July 2024 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

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Lady Justice King:

1. This is a rolled-up hearing of an application for permission to appeal, with the appeal to follow if granted, against an order dated 23 May 2024 made by Mr Justice Cusworth (“the judge”) sitting in the Court of Protection. At the heart of this appeal are challenges against the declarations made pursuant to sections 15 and 16 of the Mental Capacity Act 2005 (“the MCA”) determining: (i) that it is no longer in PC’s best interests to continue to receive clinically assisted nutrition and hydration (“CANH”) and therefore that the withdrawal of that treatment is lawful; and (ii) it is in PC’s best interest to receive palliative care in accordance with the Palliative Care Plan. The judge’s judgment is found at *NHS North Central Integrated Care Board v PC and MC and The Royal Hospital for Neuro-Disability* [2024] EWCOP 31 (T3).
2. The proposed Appellant (“the Appellant”), MC, is PC’s mother. The NHS North Central London Integrated Care Board (“Integrated Care Board”) is the 1st Respondent and the Official Solicitor is the 2nd Respondent. The Integrated Care Board and the Official Solicitor oppose the application for permission to appeal. The 3rd Respondent, Royal Hospital for Neuro-Disability (“RHN”), does not intend to play an active part in this application.

Background

3. PC was born on 11 March 1989 in Turkey and moved to the UK around September 1993. She lived at home with her mother, MC. On 28 July 2020, at the age of only 31, PC suffered a cardiorespiratory arrest and collapsed at home. A lack of cardiac output for around 30 minutes led to oxygen deprivation in her brain which caused a severe hypoxic ischaemic injury. PC has been left in a state described as a Prolonged Disorder of Consciousness (“PDOC”), at the low end of the spectrum of awareness, namely one of Minimally Conscious State minus (MCS-). She shows minimal awareness of herself, others, or her environment, and has no ability to communicate. The medical consensus is that PC’s condition is permanent with no prospect of improvement. PC’s life expectancy is potentially 10 years.
4. MC described her daughter in both her written material and in oral evidence. The description in the judgment, taken from her mother’s evidence, is of a happy, healthy young woman with aims and aspirations. PC, her mother said, was: “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”.
5. PC is cared for by the RHN, having been first admitted for long term assessment on 14 October 2020 nearly three months after her cardiac arrest. Those assessments having been completed and the diagnosis of PDOC having been confirmed, on 15 March 2021 she was transferred to a specialist nursing home which provides for long term care and management of patients in a PDOC and which forms part of the RHN. She has been cared for there ever since. All the family agree that her care by the dedicated team of specialist nursing staff at the nursing home has been exemplary.
6. In June 2023, by which time PC had been in PDOC for approaching three years, a best interests meeting was held between the RHN and PC’s family. At that meeting, a consensus was apparently reached that withdrawal of CANH would now be in PC’s

best interests. It being thought that agreement had been reached, arrangements were made in accordance with the “Prolonged disorders of consciousness following sudden onset brain injury: National Clinical Guidance”, (“the PDOC Guidance”), to obtain the second external opinion required under the PDOC Guidance at 4.10(1) before CANH can be withdrawn. The second opinion was obtained from Professor Derick Wade, Consultant in Neurological Rehabilitation and Professor in Neurological Rehabilitation at the John Radcliffe Hospital Oxford and Visiting Professor at Oxford Brookes University. Professor Wade was the co-chair of the Executive and Editorial Group responsible for the drafting of the PDOC Guidance.

7. Having seen and assessed PC, spoken to the family and read all the clinical records, Professor Wade concluded in this, his first report dated 17 May 2023, that it was no longer in the best interests of PC to continue with CANH. Accordingly, a date was set for the withdrawal to take place in June 2023.
8. Prior to that taking place, there arose a division in PC’s family, with her parents, two maternal aunts and a friend now being opposed to the withdrawal of CANH. One of PC’s half-sisters still considers it to be in her best interests for CANH to be withdrawn. No criticism whatsoever is intended of MC. There is no doubt that MC firmly believes that treatment should continue indefinitely.
9. On 2 February 2024, the Integrated Care Board, who had commissioned PC’s placement at the RHN, made an application to the Court of Protection seeking declarations under the MCA that PC lacks capacity to conduct these proceedings, and for a declaration that she lacked the capacity to make decisions regarding her medical care and treatment. The Integrated Care Board also sought an order declaring that it is no longer in PC’s best interests to continue to receive life-sustaining CANH and other life-saving treatment, and to consent to palliative care only.
10. There is no dispute that PC lacks capacity to conduct proceedings or to make decisions in relation to her care or treatment. Accordingly, the Official Solicitor was appointed to act as her litigation friend and was given permission to obtain independent expert evidence.
11. Professor Wade was asked by the Integrated Care Board to provide a further updated second opinion report. In preparation for that report, he reviewed the medical records and events since his last report in May 2023, reassessed PC and had a discussion with MC and one of PC’s sisters. The Official Solicitor decided not to obtain further independent expert evidence but rather to ask for additional information and evidence from the clinicians and to ask questions of Professor Wade.
12. In his second report dated 7 March 2024, Professor Wade set out his findings following his reassessment of PC and answered a number of questions raised by the Official Solicitor. He concluded that it remained his expert opinion that it was no longer in PC’s best interests to continue with life sustaining treatment.
13. The application first came on for hearing on 25 March 2024 but was adjourned to allow MC to be joined as a party, to be given time to consider the papers and to obtain legal representation.

14. Between that hearing and the matter coming on for final hearing on 24 April 2024, two things happened: (i) two weeks before the hearing, Professor Wade sent to the parties a paper written by him in the light of the case entitled "*Pain in patients with a Prolonged disorder of consciousness. A clinical overview to aid management*" ("*The Pain Paper*") and (ii) an application was issued on behalf of MC to adjourn the hearing in order to allow additional time for further investigations to be conducted into PC's level of awareness.
15. The judge decided to hear the medical evidence prior to considering and then refusing the application to adjourn. The judge's decision to proceed with the hearing is central to MC's application for permission to appeal.

The Clinical Medical evidence and assessments

16. Between 14 October 2020 and 15 March 2021, when she was discharged to the care of the General Practitioner ("GP") at the specialist nursing home, PC was under the care of Dr B a consultant in neurorehabilitation at the RHN. Dr B had overall responsibility for her specialist assessment, daily clinical management, treatment escalation plan and family discussions concerning her diagnosis, prognosis and discharge plan.
17. Following an assessment carried out in accordance with the PDOC Guidance, PC was found to be in a PDOC (MCS-). This remained the position at the date of her discharge to the nursing home. According to the guidelines in the PDOC Guidance, she had been in a PDOC since the end of October 2020 (more than three months after her brain injury) and it was therefore likely to have become permanent by the end of April 2021 as there had been no changes in the trajectory of her awareness behaviours.
18. During her time at the RHN, PC exhibited distress behaviours clinically characterised by moaning, facial grimacing, sweating and crying. In accordance with the PDOC Guidance, PC underwent a structured assessment for the recording of behaviour that may denote experiences of pain. She was diagnosed with pain related Paroxysmal Sympathetic Hyperactivity, a clinical syndrome which can occur in patients with severe acute brain injury. Medication was prescribed accordingly, with the family having accepted advice that the benefit of pain control outweighed the risk of increased sedation.
19. Whilst Dr B was of the view that to interpret these behaviours as experiential distress would be to misinterpret them and to risk over treatment, PC was nevertheless referred to Dr J a neuropsychiatrist who reviewed her regularly and oversaw her medication plan which medication comprised, buprenorphine patches for possible perceived pain, an antidepressant, a muscle relaxant and a drug for sympathetic hypersensitivity.
20. In her oral evidence, Dr A said that PC's "diagnosis is MCS- which means that she is on the lower end of MCS, so there is a possibility she had a tiny bit of awareness of pain and maybe of other things.... In my observations of her I have seen very little deliberate responses."

21. Upon PC's discharge to the nursing home, Dr B had made a number of recommendations which included that "[n]o further investigations relating to her disorder of consciousness were recommended unless her presentation changed."
22. Dr B concluded his written evidence in this way:

"I would like to emphasise that the vast majority of her behaviours, as have been clinically possible for her to ascertain when under my care, were negative, distressing and intolerable when compared with the narrative I had from family and friends of this young, vibrant and hopeful person."
23. The RHN nursing home is a GP led unit. Dr A has been PC's lead clinician since June 2021. She recorded that PC remains in PDOC (MCS-) with no means of communication and is fully dependant for all her care needs. More specifically, she is bed/wheelchair bound with no voluntary movement and profound cognitive impairment. She receives 24-hour nursing care and is currently stable at this low baseline. On 11 October 2021, PC was successfully weaned off her tracheostomy and decannulated and now breathes without support. She continues to be fed by PEG tube. She is doubly incontinent and has contractures to her limbs that require regular stretching.
24. The court also had the benefit of evidence from Ms B who is the Matron of the Specialist Nursing Home Service. Evidence of the type given by her, reflecting the observations of the experienced and dedicated nurses who care for patients such as PC day in and day out, are of particular value and assistance to a judge who is trying to assess the quality of life of a person in PDOC.
25. Ms B explained that she has not seen any evidence of awareness and that, for the most part, PC's eyes are closed and even when open there is no fixation or tracking to be observed. As when she was being assessed at the RHN, PC demonstrates episodes of behaviour which Ms B says could be perceived as distress with episodes of crying and facial grimacing. Whilst sometimes this is associated with personal care, on other occasions it is seen with no identifiable triggers.
26. At a meeting with MC on 22 August 2023, Dr A explained that extensive assessments had been carried out to try to understand PC's crying, but that no pattern had been identified. She said that the brain damage she had suffered and the impact on PC's autonomic nervous system might be an influential factor on her tears. She said that prescribing anti-depressants had significantly reduced her tears particularly during the night.
27. Unfortunately, these periods of 'distress' appeared to increase in the later part of 2023. PC was reviewed on 13 and 20 December and her buprenorphine (pain relief) patches increased. She was reviewed again on 29 December as she was still "often crying and in distress, but with no obvious cause".
28. Dr A was asked by Mr Lawson, on behalf of MC, about any sedative effect on PC of her medication. Dr A did not believe that the medication has a significant sedative effect. She said that PC does not exhibit any behaviours which exhibit even minimal awareness. The pain relief medication she receives had, she said, produced a

beneficial response in reducing externally observed distress. Dr A continued: “It is not possible to know whether there is any effect on (internally) perceived distress experiences by [PC].”

29. Professor Wade, when carrying out his second clinical assessment of PC on 27 February 2024, (discussed below) recorded that throughout his time with her, PC was crying and moaning and “her facial expression represented considerable distress and possible pain.” The ward sister told Professor Wade that this distressed behaviour was quite common. It tended, she told him, to abate after taking medication and then would start to return an hour or so before medication was due. His contemporaneous record of “Impairment” says:

“Repeated and frequent behaviours associated with pain or distress:

Facial grimacing and frowning

Moaning and crying”.

30. What is clear from all the evidence is that PC’s crying and appearance of distress has been a significant feature of PC’s presentation and a matter of continual concern to those caring for her. Notwithstanding regular review and assessment, the crying and grimacing behaviours continue and have been ameliorated with medication including pain relief and anti-depressants, with only varying success.

Professor Wade’s evidence on awareness and pain:

31. Mr Lawson submitted that both the RHN and Professor Wade had failed to follow the PDOC Guidance in relation to assessment of PC’s current level of consciousness and awareness. In order to see whether that is in fact the case and, if so, whether any such failures were material, it is necessary to consider what assessments took place and then to consider them against the backdrop of the PDOC Guidance.
32. MC’s case that there were inadequate assessments in relation to PC’s level of awareness, together with Mr Lawson’s wholesale attack on the evidence of Professor Wade in relation to his evolving evidence as to whether PC does or does not feel pain, form the central planks to the primary ground of appeal, namely that the judge erred in failing to grant the application for an adjournment in order for fresh neurological assessments to be carried out as to PC’s level of awareness.
33. In the first report dated 17 May 2023, which Professor Wade had prepared in order to provide a second opinion at the time when the family felt it to be in PC’s best interests for treatment to be withdrawn, Professor Wade had drawn a distinction between responsiveness, which is often seen to a limited extent in cases of PDOC, and awareness. He pointed out that the clinical observations of the staff are the most important way to assess awareness and that their observations taken together with standardised assessments of the Wessex Head Injury Matrix (“WHIM”), Coma Recovery Scale – Revised (“CRS-R”) and Music Therapy Assessment Tool for Awareness Disorders of Consciousness (“MATADOC”) had shown no evidence of any awareness on PC’s part.

34. So far as pain is concerned he said:

“...Although pain may cause her to grimace or react, these changes are probably automatic and not indicative of actual pain..... In practice, I think that she is very unlikely to be experiencing pain. However, it is notable that her observed behaviours are generally associated with pain and no behaviours associated with pleasure or happiness have been reported.”

35. Professor Wade said that there was no need for further diagnostic testing concerning her brain damage. There were no observations to raise any doubts as to her level of awareness and there was therefore no indication for any further clinical assessments of her awareness or consciousness. For these reasons, he agreed with the clinicians and with what was at that time thought to be the view of the family, namely that after approaching three years in this condition, it was no longer in PC’s best interests to continue life sustaining treatment.

36. In his second report dated 7 March 2024, Professor Wade’s view remained unchanged. In addition to his own clinical assessment carried out on 27 February 2024, he had the benefit of Ms B’s statement of 20 February 2024 which summarised the nursing observations of awareness, distress and pain. He also had the benefit of the two further assessments which had been undertaken in October 2023 using the WHIM and using CRS-R. He said that:

“These additional assessments:

- a) Confirm that here has been no significant change over the last three years, with possibly a small decline in her initial scores.
- b) Show a low level of responsiveness.
- c) Show no evidence of significant awareness or ability to discriminate between stimuli.

The observed responses were often those associated with pain in people who are aware, such as grimacing and frowning.”

37. In the light of the increase in crying and groaning, behaviours commonly associated with pain, Professor Wade addressed the issue of pain in a little more detail in his written report. He explained that it is logically impossible to give a definitive answer as to whether PC is experiencing pain “because there is no external assessment or measure of experience”. He summarised the view he held at that time as follows:

“5.16 Nevertheless, it seems likely that the experience of pain is dependent upon a widespread neural network throughout the brain, often referred to as *pain matrix*. Consciousness and awareness arise from a neural network of similar extent, and

neurological damage that impairs consciousness must almost certainly impair pain perception and awareness.

5.17 On the other hand, because pain is arguably a more basic phenomenon than consciousness, the pain matrix may be more resistant to degradation.

5.18 She is unlikely to be conscious of pain, but we should not discount the possibility.”

38. Professor Wade said that the only material change he had identified between his first and second assessment of PC was the “emergence of more pain behaviours”. He said that:

“5.32 it causes considerable distress to the nursing care team and family members who do not visit because it is distressing. Moreover as I discuss, although it is very unlikely that she has any meaningful experience of pain, it absolutely cannot be excluded and must be considered within her management.”

39. Finally on the issue of pain, Professor Wade said:

“6.17 Nevertheless, given the difficulty in stating categorically that the pain behaviours do not indicate a low level of pain experience that may be forgotten instantly but nevertheless felt, one should at least consider the pain behaviours as part of the information needed to make a decision.”

40. Professor Wade again concluded that no further investigations were needed as they would not alter any understanding of PC’s situation or any estimates on prognosis: “the estimates are firm and beyond reasonable doubt”.

41. His conclusion remained that it was no longer in PC’s best interests to continue with CANH, his reasons included that:

“g) last but not least, she exhibits frequent pain behaviours, which can be reduced using painkilling and sedating drugs, and although it seems unlikely that she is experiencing pain as a person, if she does have any experience at any level, it will be predominantly one of pain and distress.”

42. Professor Wade’s view at this stage in common with that of Dr A was therefore that it is unlikely that a person in PDOC experiences pain. That being said, given the inherent uncertainties surrounding the issue of pain and clinicians’ strong imperative to keep patients in PDOC as comfortable as possible, patients exhibiting pain behaviours are routinely prescribed pain relief.

43. Professor Wade’s view on the complex and difficult issue of pain in patients with PDOC evolved following the preparation of his second report. He was influenced by his observations of the significant pain behaviours which he had observed to be exhibited by PC on an increased and regular basis, particularly her crying and

groaning, which were behaviours that responded to pain medication and anti-depressants.

44. In the *Pain Paper* circulated on 10 April 2024, two weeks before the hearing, Professor Wade posed the question: “[i]s pain experienced only by undoubtedly conscious people, or may some degree of experience occur even in unconscious people?”
45. Professor Wade’s position as set out in the *Pain Paper* moved towards a view that a patient in PDOC may experience pain. He puts forward this proposition against the context that, unless someone can actively report or indicate their experience, “we do not know if they are experiencing pain; we can only surmise they might be”. “Very few patients”, he said, “show a complete loss of responsiveness, and responsiveness to pain is often the first and predominant type of response seen. Thus, it is tough to state unequivocally that someone has no awareness or experience of pain”.
46. He concluded by saying:

“...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 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.”
47. Against this conclusion Professor Wade drew out three “crucial consequences”: (i) that the current policy of treating people who exhibit pain behaviours in ways to minimise and control pain should continue; (ii) people should be managed to minimise the likelihood of pain and (iii) when considering best interests, the likelihood that they have experienced and will continue to experience some pain “should be a relevant, probably vital factor”.
48. It follows that Professor Wade was not advocating any change in the day-to-day management of patients who exhibit pain behaviours.
49. It is not necessary for the purposes of this application for permission to appeal to analyse Professor Wade’s paper in any further detail, as the question for the court is whether, given what Mr Lawson suggests was a complete change of view on Professor Wade’s part, there is a real prospect of MC succeeding on an appeal on the basis that the judge was wrong in refusing to adjourn the case in order for further neurological evidence to be obtained.
50. Professor Wade’s position had evolved from a view that it is unlikely that a person in PDOC will experience pain but that it “cannot be excluded”, to “we have no convincing evidence that an unconscious person cannot experience pain”. What the judge knew and was entitled to take into account was that PC was and is exhibiting significant and distressing (for all concerned) pain behaviours in the form of crying, groaning and grimacing which behaviours appear to respond to pain relieving medication. Further, that so far as expert understanding is concerned, the level of

uncertainty about how pain is experienced, if at all, by people in PDOC is such that current policy is to treat people who exhibit pain behaviours in ways designed to minimise and control pain.

51. I should make it clear that Professor Wade's evolving view about this issue had no impact upon his evidence as to PC's diagnosis, level of awareness or need for further assessment of her condition, all of which remained constant throughout, as did that of Dr B and Dr A.

Assessments and the PDOC Guidance

Assessments

52. On 14 October 2020, PC was transferred to the RHN for an extended period of assessment and rehabilitation. Whilst there, she underwent a variety of standardised assessments for patients in PDOC over a period of 4–5 months. This included: (i) WHIM on 10 occasions for a total of 5 hours 15 minutes; (ii) the CSR-R also on 10 occasions and (iii) MATADOC.
53. Of the ten times on which the WHIM assessment was carried out, on only one occasion, on 29 December 2020, was PC seen to switch gaze from one person to another spontaneously. Such a reaction was not seen on any of the remaining nine occasions, and has not been observed in the 3 years 7 months since, nor has any other sign of awareness been observed in that time.
54. In addition to these assessments, PC was subject to visual, auditory and somatosensory evoked potential testing ("EEG/EP") to complement the clinical assessments and to help with prognostication. The absence of perception and awareness behaviours observed on assessment suggested that those areas of the brain were unable to respond, which further signified severe global brain damage.
55. Following the period of assessment, Dr B concluded that PC was at the lowest end of the spectrum of awareness MCS - as defined in the PDOC Guidance. As noted above, upon PC's transfer to the nursing home, Dr B said that no further assessments of her level of consciousness were necessary absent any change in her presentation.
56. PC is subject to a care plan setting out her care requirements. Yearly reviews are carried out for each patient, this takes the form of an occupational therapy progress assessment and was carried out at the nursing home with WHIM and CRS-R scoring. No new behaviours signifying awareness were noted in PC at these annual reviews. A review took place over three sessions in April 2023. Once again, no new behaviours were noted, and the WHIM scores were consistent with previous reviews. On each occasion, the most advanced behaviour observed was frowning.
57. A further review was conducted on 16 and 19 October 2023, after the preparation of Professor Wade's first report. On these two occasions, no behaviours were observed as on each occasion the Occupational Therapist conducting the assessment was unable

to wake PC. PC also underwent two CRS-R tests when all the individual scores on the different domains were at reflex level or lower.

58. On 2 February 2024, the Integrated Care Board had made their application for a declaration that it is no longer in PC's best interests to continue to receive CANH which had led to the request for Professor Wade carrying out a fresh assessment in February 2024.
59. A key task of the Official Solicitor was to form a view as to whether further medical evidence was necessary in order to enable the court to resolve the issues in the proceedings.
60. To that end, the Official Solicitor had asked the Integrated Care Board to file and serve the following additional evidence:
 - i) A statement from Dr B.
 - ii) A supplementary report from Professor Wade *following a further assessment addressing:*
 - a) Whether there had been any material change in PC's condition or presentation;
 - b) Whether there was value in further investigations of PC's condition; and
 - c) PC's awareness in particular by reference to Dr A's statement that PC is "sometimes alert".
 - iii) PC's medical records for the preceding 3 months and all formal clinical assessments/evaluations undertaken in accordance with the PDOC Guidance.
(my emphasis)
61. The further evidence was filed and having considered it, the Official Solicitor did not consider that it was necessary to obtain independent expert evidence.
62. In order to prepare his supplementary report, Professor Wade once again conducted a full assessment; reviewing the medical records and case notes, reading the minutes of the best interest meetings and the family meeting and considering the PDOC Assessments which had taken place since his first report, namely the assessments undertaken of PC's awareness and consciousness in October 2023. Professor Wade met and discussed the case with Dr A and Dr B and had a lengthy discussion with MC and PC's sister in addition to carrying out a clinical examination of PC.
63. Professor Wade responded to each of the Official Solicitor's questions and explained that in the context of PDOC "being alert" means the same as having their eyes open and as appearing to be awake, but, in this context, it does not mean being conscious.

The PDOC Guidance

64. The PDOC Guidance of 2020 is the product of a working group who updated and clarified the *Royal College of Physicians' (RCP's) Prolonged disorders of consciousness, National clinical guidelines (2013)*. In addition to Professor Wade's role as co-chair of the group. Dr B was also part of the Editorial Group.

65. The challenges faced by the Editorial Board in reaching a consensus in this sensitive and evolving area are reflected in the foreword of the PDOC Guidance to which Professor Wade is a signatory. It says that the guidelines address some “highly emotive and topical areas in which there is currently a dearth of formal research-based evidence to guide practice.... Some areas provoked rigorous and prolonged discussion, but we have endeavoured to provide a balanced view, based on the best evidence available at the current time”. “Further systematic longitudinal data collection is urgently required in this area.”
66. The foreword concludes as follows:

“In this rapidly changing field the recommendations are likely to need updating as new evidence emerges and as international consensus develops. In the meantime, we have aimed to provide a practical and useful source of advice for clinicians who work with this complex group of patients.”
67. The Guidance has to be viewed in that context. It provides advice in a ‘rapidly changing field’ prepared by experts in that field. It should not be approached as if it were statutory guidance or binding in any way, although it is an important and valuable benchmark. The Guidance is 200 pages long and covers all aspects of PDOC from terminology, through to diagnosis, assessment, ethics and end of life. The focus of Mr Lawson’s cross examination of Professor Wade and his submissions in support of his application for permission to appeal have however been largely focused on what he submits are breaches of the Guidance, in particular in relation to assessments, which breaches, he says, have rendered it necessary for an independent expert to be instructed to assess PC’s level of awareness and also as to whether she is in pain.
68. Section 2 of the Guidance covers “Assessment, diagnosis and monitoring”. Section 2.1 explains that diagnosis rests on clinical observations of awareness that “may suggest awareness of self and the environment”. The problem of misdiagnosis of PDOC as a result of diagnostic error or a change in the patient’s condition, particularly in the early stages, means that evaluation should take place by a multidisciplinary team through careful observation over an adequate period of time. Family and friends also play a key role in the assessment and diagnosis of PDOC.
69. As set out above, PC, was transferred to the RHN on 14 October 2020 for precisely such a period of assessment which took place by the expert multidisciplinary team over a period of 4/5 months prior to the final diagnosis of PDOC MCS- being made.
70. Paragraph 3.2.3 at p78 says that “if the patient remains in chronic VS/MCS for more than 6 months without any evidence of trajectory towards improvement, they may be diagnosed as being in permanent VS/MCS”. Tragically this is the consequence of the cardiac arrest and subsequent oxygen deprivation upon this young woman, she having been diagnosed to be in PDOC at the lower end of the scale after full and appropriate assessment. At paragraph 2.2.2 “Investigations”, the PDOC Guidance says that “[n]o standard or routine investigations are needed for patients in PDOC. The general principle is that investigations are only appropriate if :(a) the result will alter clinical management; and (b) it is considered in the patient’s best interests – these must always be taken into account.” Dr B’s discharge notes that “no further assessments of her level of consciousness were necessary absent any change in her presentation” are

therefore entirely in accordance with the guidance. It should be noted that, in compliance with (a), extensive investigations was undertaken in relation to PC's pain behaviours which led to clinical management by way of medication in an attempt to manage her apparent distress.

71. The PDOC Guidance notes at 2.2.4 that “the mainstay of assessment is through the clinical evaluation by skilled professionals with specific experience of PDOC. Structured assessment using validated tools to quantify the level of response provides a sound basis for recording change over time.” It is hard to imagine any environment in which PC would receive more expert and specialist care and assessment than at the RHN nursing home. PC is continually the subject of clinical assessment by reference to her behavioural responses, hence the continued efforts by those caring for her to reduce her distress behaviours. In addition, the annual review is carried out using the WHIM and CRS-R approach in order to monitor her level of awareness.
72. Mr Lawson criticises the clinicians at the nursing home saying that the WHIM test should be administered 10 times over a period of time, that there should be a multidisciplinary approach and that the test should not be administered by an occupational therapist. With respect to Mr Lawson, that is to conflate the detailed assessments which take place over many months and which lead up to the diagnosis of PDOC with the long term care of PC which does not require standard or elaborate investigations absent any change in PC's observed level of awareness.
73. That this is the case is further underlined by paragraph 3.2.3 at p79 under “Longer-term management” which says:

“Patients in permanent VS/MCS no longer require formal review by specialist PDOC assessor, although it is good practice to conduct a brief annual follow up”
74. That leaves then the assessment carried out by Professor Wade at the request of the Official Solicitor in the context of the present application. Relevant to the application is paragraph 2.2.3 which says that “[f]ormal assessment is essential in the following circumstances”:

“As part of the assessment when making decisions about the potential withdrawal of active medical treatment (specifically CANH)”.....

“Assessment should be undertaken by a clinical team with specific training skills and experience in the evaluation of patients with PDOC. Formal standard evaluation should be performed under appropriate conditions with particular attention given to those given to those listed in Table 2.2.”

(Table 2.2 sets out the conditions for assessing the level of consciousness by reference to such issues as the environment, posture of the patient, fatigue etc.)
75. In my judgment, there can be no doubt that Professor Wade carried out a thorough and detailed formal assessment conducted in light of the Integrated Care Board's application for a declaration. He spoke to Dr B and Dr A, each of whom also filed

statements. He discussed the case with the nursing staff and the family, read all the case notes and carried out his own expert clinical assessment of PC with input from the expert clinicians and from the family. It would be simply splitting hairs to suggest that because Professor Wade gathered information from, and discussed the case with, the treating team, it did not count as an assessment ‘undertaken by a clinical team’. Each person from whom he gathered information and with whom he discussed the case had the requisite skills and experience in evaluating patients with PDOC.

76. It is against this backdrop that Professor Wade said in his oral evidence, that no further assessment was required as there had been many structured assessments “but more importantly, she had been in a setting where care staff are familiar with looking and observing and writing about people work (*sic*) in a prolonged disorder of consciousness... and would have remarked upon and detected behaviours that would have indicated awareness.” Professor Wade, in response to questions on behalf of PC, expressed his opinion that there was “no chance of even a small improvement” and that a further structured assessment to assess PC’s awareness “would be a waste of time”.
77. The judge summarised Professor Wade’s evidence as to the adequacy of the assessments as to PC’s diagnosis as follows:

“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 Judgment

78. The judge having considered the evidence of Ms B and Dr A, accepted and adopted the summary of PC’s current condition which was provided by the Official Solicitor as follows at [35]:
- 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.

79. The judge moved on to set out Professor Wade's views as they appeared in his two reports, before moving on to what he described as "his more developed conclusion" as to pain found in his *Pain* Paper and supported in oral evidence. The judge noted that in cross examination that Professor Wade had:

"42. ... 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."

80. The judge then set out the evidence, all of which is unequivocal, that PC does not experience any pleasure. The judge found it to be striking that no such experience has been identified even by the family. That was so much the case that MC's evidence was that she has been too upset by PC's presentation to visit very much recently. She said that PC looks at her with "sad eyes" and that before a recent increase in medication, she was "crying a lot, perhaps because she was in pain or sad."

81. The judge refused Mr Lawson's application to adjourn at the conclusion of the medical evidence. The judge unhesitatingly rejected at [51] any question of there being any uncertainty as to PC's diagnosis which he held to have 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."

82. He then moved on to say in relation to the issue of PC experiencing pain at [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'."

83. The judge proceeded to consider specific elements in the s4 checklist in order to reach a decision as to whether it was in PC's best interests for her to continue to receive life sustaining treatment.
84. The judge said, having heard the evidence. that he was unable to reach a conclusive view as to PC's likely wishes as to whether she would choose to remain in her present state or whether she would wish to bring her life to an end and for that reason he looked primarily at what he described as her "personal best interests."
85. In this context he said that:

"57.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.

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."

86. The judge drawing on his earlier findings, concluded that there was no real prospect of recovery or of improvement of PC's quality of life and that after four years, any progression will be negative rather than positive. Notwithstanding these conclusions

the judge reminded himself of the importance of sustaining life even where there is little hope of recovery and of the finality if treatment is withdrawn.

87. In reaching his conclusion that it is not in PC's best interests to continue to administer CANH the judge said that the principal advantage of continuing CANH was the simple preservation of life "which is of course of the utmost importance" but that:

"62...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."

88. Against this analysis, the judge concluded that the benefits of continuing CANH were clearly outweighed by the significant burdens of her continuing condition and that he was entirely satisfied from all that he had heard and read about PC that she would not wish to continue with life in her current condition.

The Grounds of Appeal

89. In summary, the Grounds of Appeal are as follows:

Ground 1: The decision not to adjourn to obtain expert medical evidence was unfair in circumstances where the only evidence was from a second opinion doctor who fundamentally reversed his opinion on the key point in the case (PC's experience of her life) while giving evidence.

Ground 2: The Court conducted its own assessment of PC's experience of pleasure, contrary to authority.

Ground 3: Failing to determine the relevance of "covert consciousness" to the assessment of people in a persistent disorder of consciousness.

Ground 4: It was an error, and contrary to authority, to decide that it was appropriate to cease treatment for someone with a low burden of care and no expressed wishes not to have care. That decision failed to pay lawful respect to the sanctity of life and PC's right to life.

Discussion and Analysis:

90. The legal framework set out in the judge's judgment was drawn from the "Agreed Summary of Legal Principles" agreed between the parties for the purposes of the

hearing. Those principles are well established and I refer to them only where relevant to the submissions made by the parties.

91. This Court did not ask for submissions from the Integrated Care Board or the Official Solicitor in respect of Grounds 2 and 3 and I deal briefly with them first.
92. So far as Ground 2 is concerned, the extensive independent evidence gathered over a number of years was that PC derived no experience of pleasure. The judge summarised the evidence before him accepting it, as he was bound to do absent any evidence to the contrary. He did not conduct his own assessment. Permission to appeal on this ground is refused.
93. So far as Ground 3 is concerned, Mr Lawson's exploration of the discrete issue of 'covert consciousness' in cross examination was very limited and was in the context of an academic paper by Professor Adrian Owen called "*The Search for Consciousness*". This brief paper explores technological developments whereby using functional magnetic resonance imaging ("fMRI") there may be demonstrated, in certain cases, residual cognition and covert awareness at some deep level. It remained however impossible to establish any form of traditional communication at the bedside. The paper records that the use of fMRI "with entirely physically non-responsive patients is still very much in its infancy" although the paper says, it has the potential to improve diagnosis.
94. Mr Lawson did not suggest that fMRI should or could be conducted on PC. This means that the judge and any other expert could only properly base their conclusion as to whether there was a correct diagnosis on the evidence available which was already before the court. The judge was entitled to conclude that PC was in a state of PDOC and that her level of awareness had been established by appropriately qualified experts. It was therefore unnecessary to have dealt expressly with 'covert consciousness' when all the evidence collected following full assessment in compliance with the PDOC Guidelines, and specifically relating to her current presentation, did not raise any clinical uncertainty. It follows that permission to appeal is also refused on this ground.

Ground 1: The application to adjourn

95. Ground 1 relates to the judge's dismissal of the application to adjourn the hearing. The judge should, it was submitted, have adjourned the hearing after the medical evidence in order to allow fresh neurological evidence to be obtained.
96. Pursuant to r.15.3(1) Court of Protection Rules 2017, the Court of Protection has a duty to restrict expert evidence to that which is "necessary to assist the court to resolve the issues in the proceedings". Those representing MC had to satisfy the judge that, notwithstanding the overwhelming evidence in relation to the diagnosis of PDOC and as to PC's level of awareness, further neurological evidence was necessary in order to resolve the proceedings. Far from answering that question, those representing MC had not complied with r.15.5 (2) and (3). No expert had been identified, there was no draft letter of instruction, no indication of the issues to which expert evidence would relate or the questions which the expert would be requested to answer. The grounds in support of the application to adjourn simply stated that "it is appropriate to carry out further investigations of [PC's] awareness".

97. In his helpful oral submissions, Mr Lawson focused on: (i) the issue that there had not been adequate assessment of PC, and that both Professor Wade and the nursing home had been in breach of the PDOC Guidance, and (ii) that Professor Wade's evidence as to 'pain' was a central point and that having changed his view on PC's ability to experience pain, it was unfair on the parties not to enquire into both that change of evidence and her awareness.
98. Mr Lawson submitted that there had been a departure from the PDOC Guidance in that there had wrongly been no full assessment of consciousness for some years. There was, he said, sparse evidence of the level of PC's consciousness and there was accordingly a need for a repeated assessment 4 years down the line. There was he said an "uncertainty as to diagnosis" which required further investigation.
99. So far as 'pain' was concerned, Mr Lawson said that it was unfair of the court to proceed on the basis of "shifting sands". Professor Wade's views on pain were, Mr Lawson said, central to the decision the court had to make, and an acceptance of his new position was not a satisfactory basis for decisions as to PC's best interests.
100. An appeal against a decision to adjourn a final hearing is a case management decision which has to be considered by an appeal court on the basis of whether the decision is fair. In *Re P (A Child)(Fair Hearing)*[2023] EWCA Civ 215, Peter Jackson LJ distilled twelve key principles from a range of appellate and ECHR authorities concerning the issue of whether it is fair to adjourn proceedings. It is not necessary to rehearse those principles here, although it is worth noting that Peter Jackson LJ followed his itemisation of the propositions at [46] by saying that: "[t]he essential touchstone is fairness and the weight to be given to any individual proposition or other relevant factor must be a matter for the judgment of the court in the case before it".
101. It should be borne in mind that the PDOC Guidance is just that, guidance, but in any event on an analysis of the guidance, there is in my judgment no basis whatsoever for the submission that the Integrated Care Board were in breach of the PDOC Guidance by not having repeated a full multidisciplinary assessment since PC moved to the nursing home, or that the annual reviews were inadequate. It is abundantly clear that there was no evidence of any improvement or increase in awareness on PC's part by the demonstration of pleasure. On the contrary, the only significant change was the increase in her crying and distress behaviours which was appropriately investigated.
102. As was acknowledge by the judge at [40], the evidence of Professor Wade as to PC's likely awareness of pain evolved during the hearing and it is undoubtedly the case that his view as to whether PC may suffer pain has changed. Significantly however, his evidence as to PC's diagnosis, her level of awareness and the need for further assessment of her condition was unaffected by his change in view with regard to her likely experience of pain. It was therefore wrong for it to be asserted on behalf of MC that Professor Wade had "fundamentally reversed his opinion on the key point in the case". In my view, as was submitted by Mr Hadden on behalf of the Integrated Care Board, Professor Wade's expanded definition of pain and his recognition that PC may have some experience of 'pain' should not be conflated with any change in his opinion regarding PC's level of awareness or consciousness, an opinion that was on all fours with all the clinical evidence and the annual reviews carried out by reference to the WHIMs and CRS-R tests.

103. The judge was entitled to conclude on the evidence that so far as PC was concerned at [57] “there was no evidence of any enjoyment of life. The only evidence is of her exhibiting discomfort and pain”.
104. Mr Lawson has neither at first instance nor on his application for permission to appeal identified an appropriate expert or told the court what difference expert neurological evidence would bring to the determination of PC’s best interests. The judge had the benefit of all the assessments set out above. The Official Solicitor gave careful consideration as to what medical evidence was required and at her request, Professor Wade answered the various additional questions she had posed in addition to having conducted a full and formal assessment such as is required by the guidance when an application to the court for an order in relation to the withdrawal of CANH is contemplated.
105. In my judgment, there is no real prospect of a successful appeal against the judge’s findings that: (a) no amount of further assessment would answer the question whether PC is capable of feeling pain; and (b) there is no evidence suggesting or indicating that PC is functioning at a higher level than all the previous assessments, or that this issue requires further investigation. Permission to appeal is refused on Ground 1.
106. I should say for completeness that whilst in this case it has not led to the granting of permission to appeal, I can understand that those representing PC felt ‘wrong footed’ by the late introduction of the *Pain Paper* which was, as I understand it, introduced other than by court direction or agreement between the parties. I would remind legal representatives who have the lead in the instruction of experts, that the filing of additional expert evidence should be done following an application to the court, which application can, no doubt, be dealt with on paper if the parties are in agreement.

Ground 4: A compelling reason for the Court to hear an appeal.

107. Ground 4 is that the judge was wrong to reach the decision he did where PC had a low burden of care and where she had not expressed a wish not to have care and he had therefore failed to pay lawful respect to the sanctity of life.
108. Mr Lawson submitted that there was a compelling issue of principle for this court to consider, namely whether it is right in any case where there was a low burden of care and no expressed wishes on the part of a patient not to have care for a judge to make an order that it is in the best interests of that patient to withdraw CANH.
109. In my judgment, there is no need for this court to undertake such a task. The legal principles applicable to these cases are clear and well established. Whilst Mr Lawson seemed to suggest that the time might have come to update or clarify the principles set out in *Aintree Hospital NHS Trust v James* [2013] UKSC 67 (“*Aintree*”), Baroness Hale’s judgment remains the lodestar which guides the courts when considering these anxious cases and it therefore remains the case that the sanctity of life is not absolute and that life sustaining treatment can nevertheless be withdrawn where it is not in the best interests of the patient. Time and again judges rightly have in mind [36] of *Aintree*:

“36. The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and

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

110. In any event, there is no merit in the individual features upon which the need for guidance was said to be based. The judge had well in mind the sanctity of life and said in terms at [62] that "...the simple preservation of life.... is of course a fundamental principle of the utmost importance". Mr Lawson sought to suggest that PC has a 'low burden of care'. Whilst it is undoubtedly the case that PC is stable as to her base line and is not the subject to regular intrusive treatment such as ventilation or regular suctioning, the judge unsurprisingly found as a fact that "the burden of her condition on PC is a heavy one". PC is reliant on nursing care for everything, and her parlous condition is as found as by the judge as set out at [79] above and included her displays of the pain behaviours which have been described. Finally, the judge gave detailed consideration as to the sparse evidence of PC's wishes and feelings and was conscious that PC had not expressed a view as to whether to receive CANH or not to receive CANH. This was a factor which he properly weighed in the balance together with the burden of care and the sanctity of life.
111. In my judgment, there is no real prospect of an appeal succeeding on Ground 4 if permission to appeal were granted and there is no compelling reason for the court to hear an appeal.

Outcome

112. PC has now been in a PDOC for 4 years with no prospect of any form of recovery. It is hard to imagine the level of grief her devoted family must feel and it is little wonder that MC and other family members have clung onto the hope that things might change, but things have not and will not change now, and even the family find it hard to visit and to see the pain behaviours PC exhibits, behaviours which are deeply distressing regardless of what PC's perception of pain actually is or may be. The reality is that PC has been assessed and reviewed at the national centre of excellence by leading experts in this field who have all agreed that her PDOC is permanent with no hope of even marginal improvement. PC could not have received better care than that given to her by the nursing staff at the RHN nursing home and the judge, in his careful and compassionate judgment, was entitled to conclude that it is no longer in PC's best interests for her to continue to receive life sustaining treatment.
113. It follows therefore that permission to appeal is refused on each of the four Grounds of Appeal and that the judge's order made pursuant to section 16(2) MCA that it is not in PC's best interests to receive CANH and that it is in her best interests to discontinue CANH and receive palliative care in accordance with the Palliative Care plan should stand.

Lord Justice Baker:

114. I agree.

Lord Justice Bean:

115. This is a very sad case, in which one can only have immense sympathy for PC's family. However, I am in no doubt that Mr Justice Cusworth's decision was correct. Accordingly, for the reasons given by Lady Justice King, I too would refuse permission to appeal.