



Neutral Citation Number: [2024] EWCA Civ 1466

Case No: CA-2024-003546

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE COURT OF PROTECTION
The Hon Mrs Justice Arbutnot DBE
COP20002405

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 29 November 2024

Before :

LORD JUSTICE BAKER

and

LORD JUSTICE PHILLIPS

XY (WITHDRAWAL OF TREATMENT)

George Thomas (instructed by **Advocate**) for the **Appellant**
Michael Mylonas KC (instructed by **Hill Dickinson LLP**) for the **First Respondent**
Sophia Roper KC (instructed by **the Official Solicitor**) for the **Second Respondent**

Hearing date : 26 November 2024

Approved Judgment

LORD JUSTICE BAKER :

1. This is an application by a woman, who I shall call A, for permission to appeal against a declaration by Arbuthnot J sitting in the Court of Protection in proceedings involving A's mother, whom I shall call XY. The terms of the declaration are that it is not in XY's best interests for clinically assisted nutrition and hydration (CANH) and ventilatory support to be continued and it is lawful for that treatment to be discontinued.
2. A few minutes ago, we informed the parties that the application for permission to appeal would be refused. This judgment sets out my reasons for agreeing with that decision.
3. The very sad background to this case can be summarised as follows.
4. XY, who is now aged 54, is a member of a large family. She has two children, A and her younger brother. She has four grandchildren, A's children. XY has seven siblings and many cousins, nephews and nieces. Most of her family live in London, but she has a large extended family living in Jamaica, including her father, who she has visited on occasions over the years, the last occasion being this time last year. Her daughter describes her as a popular person who cares deeply about other people. Within these proceedings, statements have been filed by a number of family members, four of whom, including A, gave evidence before the judge who recorded that

“they all painted a similar picture of a warm, loving, mother, aunt, sister or friend. A real character, XY was the centre of the family, a wonderful mother and grandmother, a great cook and baker, she loved dancing at home.”

A described her mother as her best friend.

5. XY is a popular member of her local community centred round her church of which she is an active member and through which she has made many friends. Her family describe her as a deeply religious person. As I will describe below, her faith is an important element in the decisions to be made about her future.
6. XY has had some health problems in recent years, in particular a history of cardiovascular difficulties. Before that, she had been very active, regularly going to the gym, and working in the NHS in a physically demanding role. After her heart problems started in 2017, she was advised to give up work. A few years ago, an attempt was made to fit her with a pacemaker. This was unsuccessful, as complications arose during the pacemaker procedure, which led to her heart having to be restarted during that procedure. In her statement in these proceedings, her daughter described what happened:

“When she went to have the pacemaker fitted the first time, I understand that her heart stopped and the doctors had to restart her heart. She did not want this to happen again because she was scared about something going wrong and that she might die. She avoided the medical procedure because she was worried that it could lead to her dying, rather than because she did not care about her health. This shows how much she valued her life: she

did not want to put her life at risk by undergoing a medical procedure that had previously gone wrong.”

7. Shortly after midnight on 6 May 2024, XY suffered a second cardiac arrest at home. Her son, who was in the house, called the emergency services and a team of paramedics arrived a few minutes later. As the judge observed in her judgment, this was a shocking and deeply upsetting experience for her son. CPR was commenced shortly afterwards but despite strenuous efforts circulation was not restored until 1.45 that morning. It follows that XY had a period of hypoxia lasting over an hour. She was taken by ambulance to the Trust’s hospital and, after she had been intubated, she was admitted to the intensive care unit, where, over six months later, she remains, with 1:1 nursing care.
8. After admission to the ICU, XY went into another phase of cardiac arrest. She was successfully resuscitated again, but analysis revealed major metabolic problems, including injuries to her kidneys and liver. The doctors decided to establish continuous renal replacement therapy. A nasogastric (NG) tube was fitted through which she was given CANH and an endotracheal (ET) tube attached to provide ventilatory support. Thereafter her respiratory and cardiovascular status improved. She also recovered from the liver and kidney injuries, allowing renal replacement therapy to be discontinued. Amongst other problems, she suffered significant tongue swelling, attributed to injury during seizure activity, which required the introduction under anaesthetic of various intra-oral devices to prevent her biting her tongue and suffering further injury. Although the tongue injury is much improved, this remains an ongoing issue.
9. By 23 May, she was occasionally opening her eyes, but with no clinical evidence of fixation or tracking or other signs of responsiveness. This amounted to the emergence from coma into the status now called prolonged disorder of consciousness (PDOC). As summarised by Dr Dominic Bell, one of the expert witnesses whose instruction is described below, the overall picture over the following months was one of a perceived increase in the frequency of spontaneous eye-opening. The unanimous view of her clinical team, doctors and nurses, is that this has not been accompanied by any evidence of volitional movement or markers of responsiveness. This position is disputed by her family, many of whom have visited her regularly and assert that they have witnessed purposeful eye movement in response to voice or noise, blinking to command, squeezing of the hand and responsive movement of her feet.
10. Extensive examination through CT scanning and EEG has demonstrated that XY suffered severe generalised hypoxic ischaemic brain damage, atrophy and progressive shrinkage of her brain. She continues to be provided with CANH through the NG tube and ventilatory support through the ET tube. She receives the full range of conventional ICU physiological support. The opinion of her treating clinicians at the hospital is that she is in a prolonged disorder of consciousness at the most severe end, with no hope of recovery. They concluded that it was not medically appropriate to carry out a tracheostomy or offer any additional treatments if new problems arose.
11. Understandably, members of her family remain hopeful that the doctors are wrong and that some recovery is possible, relying in part on what they believe to be some responses to various forms of stimulation. The treating doctors maintain that what they have seen are in effect involuntary movements and are not indicative of any neurological response. They came to the conclusion that there was no benefit to XY in maintaining

life support and it would be in her best interests for CANH to be withdrawn, with appropriate palliative care being provided. Her family, however, do not accept this conclusion. They maintain that there is a chance of recovery and have explored other options for treatment and care.

12. An external expert opinion was commissioned from Professor Derick Wade, consultant in neurological rehabilitation at the John Radcliffe Hospital, Oxford. He conducted his own examination of XY and spoke to members of her family. He concluded that she was “at the lowest end of the spectrum of responses and of awareness”. He described the family’s observations as reported and shown to him on video recordings as automatic responses or spontaneous behaviours commonly seen in unconscious people. He advised that no further investigations were needed and that structured clinical observations suggested by national clinical guidance would be of no benefit in her case. Professor Wade advised that the choice was between continuing the current treatment until she dies or planning to stop current treatments in a way that minimised the risk of pain and distress. He concluded that continuation of the current care was not in her best interests. There was no prospect of any significant improvement in her level of neurological function.
13. On 3 September 2024, the hospital Trust started proceedings in the Court of Protection seeking declarations that XY lacked capacity to make decisions in connection with her medical care and treatment, and that it was lawful and in her best interests for life-sustaining treatment to be discontinued. Under a case management order on 27 September, the Official Solicitor was appointed to act as XY’s litigation friend and A was joined as second respondent to the proceedings. Extensive directions were given for the filing of evidence, including the instruction by the respondents of medical expert witnesses. By a recital to the order, it was recorded that the Trust had agreed to obtain a second opinion as to whether a tracheostomy was clinically appropriate. A transparency order was made in accordance with Practice Direction 4C of the Court of Protection Rules.
14. The Trust duly commissioned a second opinion on the question of a tracheostomy from Professor Maria Ostermann, consultant in intensive medicine at Guy’s and St. Thomas’s Hospital. In a report dated 10 October, Professor Ostermann advised that a tracheostomy was not clinically appropriate.
15. Dr Dominic Bell was instructed by A’s then solicitors to carry out an assessment. As the judge recorded, Dr Bell has had 34 years of consultant experience in neuro-critical care, having been until 2023 a consultant in intensive care at Leeds General Infirmary. During this time, he had been responsible for clinical care and best interests decision-making for patients with brain injuries of varying severity, including those resulting from cardiac arrest. Over the past 20 years, he has been instructed in a number of cases to assist the court in the field of end-of-life decision making, assessment of capacity and determination of best interests in relation to medical care. For the purposes of his assessment, Dr Bell considered all the medical records, undertook a direct assessment of XY, conducted interviews with senior members of the clinical team and had a discussion with A.
16. Dr Bell noted that the original renal and hepatic injuries which had followed the hypoxic incident had resolved. This was not, however, indicative of an optimistic prognosis so far as the brain injury was concerned. As the judge recorded in her

judgment, the medical evidence was that, whilst kidneys and the liver are resilient and are able to regenerate from cell death, the brain is not, unless only part of the brain is affected, for example by a stroke.

17. During his examination of XY, Dr Bell noted her eyes opening and closing at random intervals of 5 - 90 seconds, unconnected with any degree of environmental stimulation. There was no movement of the eyes or head responding to calling her name, and no detectable response to a loud clap or auditory startle. When her eyes were open, there was no evidence of any fixation on a static object or mobile light source, nor evidence of visual tracking. It was Dr Bell's opinion that those features indicated the absence of any processing of retinal information. The only potential marker of motor responsiveness were minor movements of the feet, but Dr Bell concluded, given the absence of any other evidence of a volitional response, and no accompanying changes in facial expression or monitored physiological parameters, that these represented a spinally mediated reflex in the context of the generalised increase in tone due to loss of cerebral control. Other perceived responses, for example to pressure to the fingers and toes, were not accompanied by any features of discomfort or change in the monitored physiological parameters (i.e. changes in heart rate or blood pressure). The only intervention that did produce any material changes of this sort was reported to be the manipulation of devices in her mouth to prevent further injury to the tongue. It was Dr Bell's opinion that this response was understandable physiologically as a brainstem reflex.
18. In his report, Dr Bell put forward the following interpretation of XY's clinical condition:
 - “4.1. My overview of the above clinical picture would be that XY is at the lowest point of the PDOC spectrum ... and would historically be referred to as in a persistent vegetative state.
 - 4.2. The emergence from coma, a state of absolute unresponsiveness, to one of apparent 'wakefulness' identified by phases of periodic spontaneous eye-opening, but without any markers of awareness of self or the environment, is what defines XY's position on the spectrum.
 - 4.3. This condition is generated by loss of the areas of the brain responsible for higher brain function, but leaving those components of the brain, predominantly the brainstem, with less refined function and correspondingly greater resilience to hypoxic ischaemic brain injury, largely intact and functional.
 - 4.4. The emergence of the so-called sleep-wake cycles reflects the preservation of the reticular activating system in an injury of this nature, a complex network of nuclei within the brainstem that coordinates key functions that are intrinsic to homeostasis and survival, including ventilatory drive and cardiovascular control.
 - 4.5. The presence of sleep-wake cycles in an injury of this nature does not therefore herald improvement towards conscious

awareness during phases of so-called ‘wakefulness’ whilst the patient’s eyes are open.”

19. The fact that she had initially suffered complete renal failure was “a marker of the magnitude and duration of the primary phase of hypoxia ischaemia” to a degree “that irreversible neuronal death will have occurred in virtually all areas of the brain other than the fundamentally resilient brainstem”. That indicated that “the neurological prognosis was that she would remain at the low point of the PDOC spectrum, with an extremely limited possibility of any progression into a minimally conscious state.”

20. In their interviews with Dr Bell, members of the treating team all confirmed their support for the discontinuation of life-sustaining treatment on a best interests basis and the provision of palliative care. In particular, the matron and senior sister, who had both been familiar with XY from the time she was admitted to hospital

“confirmed a nursing consensus that over this timeframe XY had not demonstrated any intentional movements, any motor response to a request for the same, or any facial expressions generally interpreted as associated with pleasure, or discomfort or distress The nursing team confirmed that there was no perceived change in the level of responsiveness to attendant family members, and that no one had observed the motor responses that the family believed were present.”

21. In her interview, A told Dr Bell that she thought her mother was slowly recovering and would continue to make progress if given the chance to do so. Asked about the best outcome, A replied “I’m not God, but if she has life, that is enough”. She confirmed to Dr Bell that that she had never had any discussion with her mother about what would be a minimal acceptable quality of life in these circumstances. Dr Bell noted the family’s strong religious views but concluded there was no point of reference as to the patient’s values and beliefs when considering best interests. He reported A’s “enduring position” as being: “I just want them to give mum a fighting chance”.

22. Given her position at the lowest point on the PDOC spectrum, and his opinion that it was impossible that she would achieve a meaningful quality of life, Dr Bell concluded that best interests decision-making would simply favour withdrawal of treatment. He considered the options suggested by the family, in particular a tracheostomy, which in his view would have to be accompanied by a feeding gastrostomy, with a view to moving XY out of the ICU. He concluded:

“It is difficult to consider that either of these interventions could be considered as in XY’s best interests, when there is no prospect of any recovery from the extremely low point on the PDOC, and no prospect of being free from intrusive and invasive medical and nursing interventions. On that basis, I am forced to conclude that it is no longer in [her] best interests to receive the currently multifaceted life-sustaining medical treatment and that it would be correspondingly appropriate to withdraw the key components of the endotracheal tube and an artificial airway and the accompanying ventilatory support.”

He advised that the detail of how that process should be managed should be left to the treating team.

23. In a supplemental report, Dr Bell responded to questions posed on A's behalf. He confirmed his view that a tracheostomy and inserting a feeding gastrostomy were not clinically indicated and, as an additional invasive procedure, not in her best interests. He described difficulties and risks which would arise in attempting these procedures for a patient in XY's condition. Secondly, in response to a question whether, if provided with a tracheostomy and a gastrostomy, XY could be cared for outside hospital, he said:

“I do not believe that XY would be accepted for step down to a rehabilitation facility, given that she has no realistic prospect of benefiting to the point of achieving a quality-of-life that was meaningful for her. It is feasible that one or other longer-term care facility for severely brain injured patients would be prepared to accept XY with a tracheostomy and feeding gastrostomy, but this would usually only take place after a protracted period in a specialised assessment centre.”

24. In addition to the reports from the three experts and the consultant in intensive care at the Trust's hospital, the court was provided with an attendance note from Ms Laura Hobey-Hamsher of Bindmans LLP, instructed by the Official Solicitor, who visited the hospital, met XY, and spoke to members of the clinical and nursing staff.
25. A statement was filed by A, to which were exhibited statements from family members and friends. In her statement, A set out some details of her mother's background and the events leading to her admission to hospital. She then put forward her perception of her mother's progress in hospital:

“Since my mum has been in hospital, she has improved a lot, and her medical team have sometimes recognised this but not always. When she was first admitted to hospital she could not open her eyes and she did not respond to anything around her. She was very unwell. From around June onwards, she started to open her eyes and look around the room. Now she opens her eyes every day and her eyes are open wide. She is very different to how she was in the first couple of weeks after she was admitted. My understanding is that she has now progressed into a sleep – wake cycle, whereas before she was not. I think that my mum's awareness of her surroundings and people visiting is improving every day. When people speak to my mum, she has started to look towards where she hears the voice coming from. She recently started to look me and my family in the eye, and in recent days she has started to stare at our clothes when we are wearing bright colours. She responds to the door opening and looks in that direction.”

A gave further examples of her mother responding, for example by blinking on request, trying to squeeze the hands of family members. A said:

“I think that these are her ways of showing us that she knows that we are there and she can hear us because she can’t communicate in any other way at the moment. She wants us to know that she is fighting and that she just needs more time.”

A expressed concern that the sedation provided to her mother prevented her from being able to respond when examined by doctors, including Dr Bell.

26. A then set out her views about her mother’s wishes and feelings. At paragraph 28 of her statement, she said:

“My mum is a committed Christian, like the rest of my family. She has a strong faith and believes that it is God’s choice when someone lives and when someone dies. My mum has remained alive despite the odds being against her since May when she suffered the cardiac arrest. On 6 May my mum died and was brought back to life. My mum would believe that there is a reason that God brought her back, and therefore that she is here for a purpose. To go against God’s will would be wrong. If God had wanted her to die then she would have died already and she would not have been brought back to life.”

At paragraph 31, A continued:

“Although my mum and I never really spoke about what she would want to happen in these circumstances, I know that she would want to be given the chance to survive. She is a fighter and she believes that it is God’s choice when someone dies. She would want it to be up to God when she dies, rather than because the medical team make an active choice to remove her life support. If God did not want her to live when she had the cardiac arrest in May, then she would have died then and she would not have been brought back to life. The fact that she is still alive now after her body has been through so much trauma shows that it is not her time yet, and God will decide when it is her time. To withdraw life support prematurely would be to go against what God wants for my mum and what my mum would want, and what my family would want.”

27. A’s evidence about her mother’s responsiveness, and about her likely wishes and feelings, was supported by the other statements from family members and friends.
28. At the hearing on 5 and 6 November 2024, the Trust’s application was supported by the Official Solicitor but opposed by A and the rest of the family. All the parties were represented by leading counsel with extensive experience in serious medical treatment cases. The judge heard evidence from the treating consultant, who informed her of recent CT scans which had demonstrated a deteriorating situation in XY’s cerebral cortex. Professor Wade, Dr Bell, A and three other members of the family also gave evidence. After submissions, judgment was reserved and delivered five days later.

29. In her judgment, the judge summarised the history of XY’s collapse and admission to hospital. She set out in some detail the evidence she had heard about XY herself from family members, including their evidence that she was showing signs of recovery, but also recorded that the medical evidence was at odds with the family’s observations. She set out the medical evidence given by the treating consultant, Professor Wade, and Dr Bell. The judge then summarised the parties’ submissions. In particular, she recorded the submissions by leading counsel for A, who had relied on the evidence from her family and friends.

“They say that XY is aware of her environment and of them. They believe it is too early to give up with her not because they do not understand the bleakness of the medical evidence but because they believe in the power of faith and in miracles. Faith is a considerable component of who XY is. The family and friends of XY believe she still has tasks to do including caring for her [teenage] son and that a miracle may ensure her recovery and [she] would choose life in these circumstances.”

30. Next the judge referred to a document agreed between the parties setting out the legal framework. She cited the key passages from the judgment of Baroness Hale in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 at paragraphs 22, 39 and 45, and other legal principles from the authorities, including that

“There is a strong presumption in favour that it would be in XY’s best interests to stay alive, and her rights under the European Convention on Human Rights are to be considered.”

Counsel had emphasised the importance of the guidance given by Cobb J in *PL v Sutton CCH and others* [2017] EWCOP 22, and the judge proceeded to follow that approach when analysing the issues in this case.

31. She began by finding that XY lacked capacity to make a decision. Turning to best interests, she started by analysing the evidence about her current condition.

“104.There is no doubt she has suffered what is termed generalized brain damage. The depth and severity of the hypoxic ischemia was shown by the brain swelling soon after 6 May 2024 and the lack of kidney function from which she recovered after treatment. EEG tests have been undertaken (about five) and show no normal brain activity and arguably a worsening position. The most recent CT scan on 22 October 2024, shows a deteriorating situation in her cerebral cortex. The cells are gradually dying or atrophying.

105. XY has no discernible level of consciousness. The treating consultant and the experts say that what she has is reflex movements of her feet, eyes, hands and a sleep/wake cycle. She has a prolonged disorder of consciousness which is at the lower level of the spectrum.

106. The family have said that she tracks them with her eyes or squeezes their hands in response to what they ask her to do, but sadly none of the nurses and doctors or experts including Dr Bell have observed this happening.

107. The expert evidence is unambiguous. I find that XY does not track with her eyes nor does she respond to voices or commands to squeeze their hands. I can understand how a family who wish that this very much loved family member should recover are misinterpreting what they see. They see responses to their care rather than the reflexes controlled by the brain stem that the medical specialists identify. That is not to say that at some level XY is [not] getting comfort from their touch, but it is not a conscious sensation.

108. The original injury was of such severity and of such duration that as Dr Bell said it would be “outside all accepted medical knowledge” were XY to be responding to their requests.

109. It is sad to say that I find XY has no awareness of her family’s presence but what they are witnessing is spontaneous and not purposeful movement.”

32. In that context, the judge considered other factors relevant to the decision whether it was in XY’s best interests for clinically assisted nutrition and hydration to continue to be delivered. She began by considering evidence about XY’s wishes and feelings, values and beliefs:

“111. XY has never stated her views about clinically assisted nutrition and hydration or on sustaining her life artificially in the circumstances where she is totally dependent on others and cannot function in any of the ways she used to, where she is not aware even that her family is visiting her.

112. Despite not being in the best of health, she never had that sort of conversation with her daughter (or anyone else). We do not know how she would feel in the current situation that she finds herself in. We do not know what she would feel about the enormous pressure being placed on her family and friends of this very long drawn out, tragic situation.

113. She worked in a hospital and is likely to have come across death and serious illness there but we do not know how she would feel about the continued treatment when the specialists and experts say it is futile. She was a woman of faith, but I question whether this loving mother and grandmother would have wanted the burden of the treatment to continue. She may have wanted her family to be relieved of the long drawn out pressure they are under.

114. I appreciate the family know her best, particularly A, but I am not convinced that this matriarch who always put her family first would have wanted them to continue going through what they have been.”

33. With regard to XY’s current quality of life, the judge found no evidence that she felt any enjoyment and concluded, on the basis of the medical evidence, that her enjoyment of life would never return. The judge found “the answer to the question of whether she suffers pain or distress is neutral” but concluded that “in the absence of any evidence of enjoyment or distress, I find the quality of [her] current life to be poor.” As to prognosis, the judge concluded that, if CANH continued, there was “no real prospect of any recovery of any of her functions”.

34. The judge then considered the wishes and feelings of the family:

“The family and friends in evidence ask for XY to be given more time. Six months is not enough for her and they want her to be given more of a chance at life and of a miracle. They described her as a fighter and if anyone could survive what had happened she would. They said the fact that she had remained alive for six months was an indication of her strength and of God’s will. She had lots more to do in life.”

She added:

“I admire the family and friends’ commitment and love for XY. They have shown dignity and grace in the face of a situation that must have tested them beyond anything that they had experienced before. They have done everything they can to keep her alive.”

The judge referred to the principle of the sanctity of life and XY’s right to life under ECHR, adding that she had “to consider whether a decision to discontinue clinically assisted nutrition and hydration is proportionate and necessary in her particular circumstances”. Finally, the judge returned to the family, saying:

“I said above the family have done as much as they could possibly have done in the circumstances. Their devotion is truly inspirational and I can understand it, now I have heard evidence of the sort of extraordinary woman XY is.”

35. The judge then set out her conclusions in these words:

“134. I have found no prospects of XY recovering to a state where she would recognize family members or even be aware of them. She has had six months when she might have improved or recovered to an extent, but has not. I have pondered long and hard about the wishes of the family and friends for XY to have more time. I have given weight to their views. I have attempted also to put myself in XY’s place in this tragic situation.

135. Having taken all I have set out above into account especially the views of this loving devoted family, I find it is in XY's best interests and proportionate and necessary that I grant the application. The futility of continuing further treatment and the increasing deterioration of XY's brain outweigh the family's views and what they consider might have been XY's views in the circumstances.

136. It is not in XY's best interests for the treatment to continue. It is therefore lawful to withdraw clinically assisted nutrition and hydration in the way suggested in the care plan."

36. Under the order made at the conclusion of the proceedings, the judge declared that XY lacked capacity to conduct the proceedings and take decisions as to her medical treatment, including the continuation of life-sustaining treatment, and that it was lawful in her best interests to be treated in accordance with the Trust's palliative care plan. The judge further ordered (under paragraph 3 of the order) that it was not in XY's best interests for CANH and supplementary ventilation to be provided after 22 November 2024 and (under paragraph 4) that it was lawful and in XY's best interests that (a) no later than that date, life-sustaining treatment be withdrawn, (b) thereafter she receive palliative care, initially at the Trust's hospital with consideration being given to whether XY can be transferred elsewhere, and (c) she be provided with such treatment and nursing and palliative care as may be appropriate to ensure that she suffers the least pain and distress and retains the greatest dignity. It was further ordered that the Trust's clinical team and A should, by 15 November, discuss and agree a date for the withdrawal of treatment by the date specified, with liberty to refer further issues to the judge if available. The judge refused an application for permission to appeal.
37. On 19 November 2024, A filed a notice of appeal to this Court. On the following day, I gave directions for an oral hearing of the application for permission to appeal on 26 November, and stayed paragraphs 3 and 4 of the judge's order pending determination of that application.
38. At the point when she filed the appeal notice, A was unrepresented. Subsequently, Mr George Thomas was appointed via Advocate to represent her pro bono. This Court is extremely grateful to him, and to the staff at Advocate, for ensuring that A, who is in effect representing XY's family, was legally represented before us. The other parties were represented as they were before – the Trust by Mr Michael Mylonas KC and the Official Solicitor by Ms Sophia Roper KC. We are also grateful to them, and their instructing solicitors, for their contribution which has enabled this urgent application to be heard and determined promptly.
39. At the outset of the hearing, we made a reporting restrictions order in conventional terms to prevent the identification of XY and her family.
40. The grounds of appeal served with the appeal notice, when A was acting in person, can be summarised as follows.
 - (1) The judge failed to give sufficient weight to evidence presented by XY's family regarding her responsiveness to familiar voices and stimuli.

- (2) The judge overly relied on evidence from the NHS Trust’s experts and did not seek dissenting or alternative opinions. The absence of independent assessments deprived XY of a full and balanced evaluation.
 - (3) The Mental Capacity Act 2005 (“MCA”) requires consideration of an individual’s known beliefs, wishes, and values when assessing their best interests. XY’s identity as a person of faith, her belief in miracles, and her family’s testimony about her desire to continue fighting for life were inadequately addressed.
 - (4) The judge failed to comply with the State’s positive obligations to protect life under Article 2 of ECHR. This duty requires that life-sustaining treatment not be withdrawn unless it is conclusively shown to no longer serve the patient’s best interests. The failure to seek independent medical assessments to confirm the diagnosis of brain death undermined the proportionality of the decision and violates Article 2.
 - (5) The decision to withdraw treatment was disproportionate, given the presumption in favour of life under English law and international human rights principles. XY’s observed responses suggest some level of interaction with her environment, which could warrant further exploration of care pathways, including palliative or neurological interventions.
 - (6) The decision also infringed Article 3 of ECHR – the prohibition of inhuman or degrading treatment. Evidence presented in court indicated that XY’s physiological responses, such as increased heart rate, could signify discomfort. The lack of clarity about her capacity to experience pain raises serious concerns about the adequacy of the proposed palliative care measures.
 - (7) The decision to withdraw treatment without conclusive evidence of brain death risks reducing XY’s dignity, particularly given her observed responses. Ensuring dignity in the final stages of life is a fundamental principle of Article 3, which was not adequately safeguarded in this case.
 - (8) The judge acknowledged that XY’s family is the best source of her wishes, yet their consistent testimony regarding her faith, values, and desire to continue life was not given sufficient weight. The best interests analysis failed to balance clinical assessments with moral, ethical, and personal considerations.
41. At the outset of the hearing, Mr Thomas acknowledged that there was considerable overlap between these grounds. Whilst not abandoning any of the arguments, he indicated that he would focus his submissions principally on the grounds that I have summarised as (1) and (3) above. His argument was that this Court should grant permission to appeal because there was a real prospect that the applicant would succeed in showing that the judge erred in the assessment of best interests because
- (1) she did not attach sufficient weight or give sufficient consideration to the evidence about XY’s responsiveness given by A and other family members, and
 - (2) she failed to take into account the evidence about XY’s beliefs and values and consequently her likely wishes and feelings, as required by s.4(6) of the MCA.

42. Mr Thomas took the court to the family's evidence about their observations of XY's responsiveness. He stated that there had been no substantial challenge to this evidence nor any questioning that could have led the court to conclude that it was unreliable. He accepted that there was contrary evidence from the nursing staff on the ICU but submitted that it was not on the same scale as the family evidence. He acknowledged that this did not override the medical evidence or the evidence from CT scans and EEG recordings, but submitted that that evidence was itself not conclusive. He submitted that the judge had been wrong to say, at paragraph 112 of her judgment, that "we do not know how she would feel in the current situation". The clear evidence from members of her family was that her faith and devotion to her family would lead her to want to remain alive. Mr Thomas relied in particular on the passages in paragraphs 28 and 31 in A's statement quoted above. He submitted that there was no reason to believe that she would not apply her long-held belief that it was God's decision whether she lived. Any assessment of a person's values had to be conducted on a balance of probabilities. Here, on one side, there was compelling evidence about XY's long-held beliefs and values. On the other side, there was mere speculation. Thus the only conclusion the judge could have reached on the evidence was that XY would want the treatment to continue.
43. Mr Thomas accepted that this argument did not mean that a best interests assessment would lead a court to dismiss the Trust's application. But there was a real prospect that an appellate court at a full hearing would conclude that the judge's evaluation of this important element in the best interests evaluation assessment was wrong and that there should be a reassessment by another judge.
44. Mr Thomas cited observations of Peter Jackson J, as he then was, in *Wye Valley NHS Trust v B* [2015] EWCOP 60 at paragraphs 14 to 15 and of Cohen J in *Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust v TG and another* [2019] EWCOP 21 at paragraphs 24 to 26, to emphasise the importance of having regard to a person's religious faith in the evaluation of their wishes and feelings, beliefs and values.

Discussion and conclusion

45. This is an application for permission to appeal. An appeal against a judge's decision will only be allowed where the appeal court is satisfied that the decision was (a) wrong or (b) unjust because of a serious procedural or other irregularity. Permission to appeal can only be granted where there is a real prospect that the appeal will succeed or there is some other compelling reason for the appeal to be heard.
46. In his clear and articulate presentation, Mr Thomas was right to focus his submissions on two grounds of appeal. Having now read all the papers and considered submissions, I conclude there is no merit in the other grounds originally advanced by A. As Mr Thomas acknowledged, if best interests are assessed in accordance with the principles set out in the MCA and the Code of Practice, and professional guidance available to doctors, the procedural safeguards required under Articles 2, 3 and 8 of ECHR will be satisfied. I conclude that there has been a scrupulous adherence to those established procedures. Furthermore, the argument that the judge overly relied on evidence from the Trust's experts and did not seek dissenting or alternative opinions is unsustainable. In his submissions, Mr Thomas observed that parties to litigation have varying degrees of involvement in the instruction of experts, that his client had accepted advice about

the instruction of Dr Bell, and was now of the view that he was not independent of the medical establishment. There is no basis for the implied suggestion that Dr Bell has not provided an independent and objective opinion. A's representatives were given an opportunity to instruct an expert medical witness and Dr Bell was duly instructed on her behalf. He reached a conclusion that supported the Trust's application. In those circumstances, there was no obligation on the court to seek an alternative opinion.

47. Turning to the first ground on which Mr Thomas concentrated his submissions, the judge was plainly fully aware of the extent of the evidence from family members about XY's responsiveness. As Mr Thomas emphasised, this evidence came not only from A but from other family members and friends. A number of them, in particular A herself, have been very regular visitors, spending several hours each day by her bedside. A was able to give evidence about specific incidents when she had seen her mother move in a way which suggested she was responding to stimuli. I do not, however, accept Mr Thomas' submission that this evidence before the judge was unchallenged. It may be that A was not cross-examined on her observations. But the challenge came from the unanimous evidence from the clinical and nursing staff that they had seen nothing to indicate any awareness in XY, and from the clinical and expert evidence that the evidence from CT scans and EEG recordings was indicative of a PDOC at the lowest end of the spectrum. Whilst it is likely to be true that nurses were not constantly present at the bedside in the way that A has been for many hours, there has been a high level of specialist nursing attendance, as is established procedure in an ICU.
48. The judge gave conspicuously careful attention to all of the evidence about this issue. Her decision to prefer the evidence of the clinical and nursing staff about the extent of XY's responsiveness, and the interpretation of the evidence advanced by Dr Bell and Professor Wade, was plainly open to her on the evidence. There is no real prospect of the Court of Appeal finding that she was wrong to reach that conclusion.
49. When considering the second ground on which Mr Thomas focused, it is important to have regard to the relevant statutory provisions. S.1(5) of the MCA provides that "an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests". S.4 lays down principles to be applied by a court when determining what is in a person's best interests. Under s.4(2), the court must consider all the relevant circumstances. Under s.4(6), it must consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, the beliefs and values that would be likely to influence her decision if she had capacity, and the other factors that she would be likely to consider if she were able to do so. Under s.4(7), the court must also take into account, if it is practicable and appropriate to consult them, the views of anyone engaged in caring for the person or interested in her welfare as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).
50. In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, Baroness Hale of Richmond said (at paragraph 39):

"The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and

its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.”

Of particular relevance to the present case is Baroness Hale’s further observation at paragraph 45:

“The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. 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. In this case, the highest it could be put was, as counsel had agreed, that ‘It was likely that Mr James would want treatment up to the point where it became hopeless’. But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.”

51. The evidence before Arbutnot J in this case was that XY’s religious faith was central to her life. It was of the utmost importance to her. It was therefore incumbent on Arbutnot J to take into account the evidence about her beliefs and values when “making the choice which is right for [her] as an individual human being”.
52. My reading of her judgment is that she took that evidence into account. Her evaluation of the evidence of XY’s wishes and feelings, beliefs and values, was conducted in accordance with s.4(6) and (7) of the Act. But important though her beliefs and values undoubtedly were, they were one factor in the overall evaluation of best interests. They had to be considered in the context of the totality of the evidence.
53. In this case, the magnetic factor in the judge’s evaluation was the evidence about XY’s medical condition. As the judge concluded at paragraph 104, she had suffered generalized brain damage. A marker of the depth and severity of the hypoxic ischemia was shown by the renal failure she suffered after her collapse. EEG recordings showed no normal brain activity. The most recent CT scans showed “a deteriorating situation in her cerebral cortex. The cells are gradually dying or atrophying.” The tragic truth is that XY is in what is now called a prolonged disorder of consciousness at the lowest end of the spectrum. Her family retain a degree of hope but the unanimous medical opinion is that there is no prospect of recovery. There is no realistic proposal of any further treatment. Her treating doctors and the experts instructed in these proceedings advise against a tracheostomy. The court cannot compel a doctor to provide treatment against their professional judgment. There is no realistic prospect that she will ever be able to leave the ICU.

54. The judge was obliged to consider the family's clear evidence about XY's faith in the context of her present circumstances which, as Mr Mylonas submitted on behalf of the Trust, she could never have envisaged. As Ms Roper submitted for the Official Solicitor, the fact that she had a religious faith, and believed that it is God's choice when someone lives and when someone dies, does not lead to an inference that she would have wanted to continue treatment in these circumstances. There is also force in Ms Roper's further submission that the family's views about what XY would have wanted are situated in their belief, contrary to all the medical evidence accepted by the judge, that there is a prospect of recovery.
55. In those circumstances, there is no real prospect of the Court of Appeal concluding that the judge erred in her approach to XY's beliefs and values and wishes and feelings. On the contrary, she gave those issues particularly careful and sensitive attention. Although she did not recite the evidence about XY's religious faith in detail, I have no doubt that she had it in mind and took it into account. In the course of summarising submissions, she recorded A's case that "faith is a considerable component of who XY is" and that she "would choose life in these circumstances". In her final analysis, the judge acknowledged that XY was "a woman of faith". But in considering the weight to be given to her faith, and to the family evidence about her wishes and feelings, the judge made a number of pertinent observations. She observed that XY "has never stated her views about clinically assisted nutrition and hydration or on sustaining her life artificially in the circumstances where she is totally dependent on others". This led the judge to conclude that "we do not know how she would feel in the current situation that she finds herself in" and "we do not know how she would feel about the continued treatment when the specialists and experts say it is futile" and to "question whether this loving mother and grandmother would have wanted the burden of the treatment to continue." In these observations, the judge was plainly following Baroness Hale's observation in the *Aintree* case. XY's wishes might well have changed in the light of the stresses and strains of her current predicament.
56. This evaluation was plainly open to the judge on the totality of the evidence. The applicant and other members of the family remain convinced that, because of her faith, XY would have wanted the treatment to continue. I have no doubt that the judge took their strong views about XY's wishes and feelings into account, as she was required to do under s.4(7). But she was entitled to entertain doubts about what XY would have really wanted in these terrible circumstances, and equally entitled to conclude that the family's evidence about her wishes and feelings was outweighed in the best interests analysis by other factors, in particular her very serious and deteriorating medical condition. As she said in her conclusion, "the futility of continuing further treatment and the increasing deterioration of XY's brain outweigh the family's views and what they consider might have been XY's views in the circumstances."
57. I endorse what the judge said in concluding her judgment. This family has done as much as they possibly could have done for XY and their devotion to her is truly inspirational. But in the circumstances, I conclude that there is no real prospect the Court of Appeal concluding that the judge's decision was wrong. I cannot identify any other compelling reason for the appeal to be heard. In those circumstances, permission to appeal must be refused.
58. In submissions, Mr Mylonas accepted that there should be a variation of the timetable set down by the judge for her order to be implemented. He proposed that this Court

should stipulate that treatment be withdrawn no later than five days after delivery of our judgment. Today is Friday. The family have spent part of the week in court. I would therefore propose that we amend paragraphs 3 and 4 of the judge's order by replacing "22 November 2024" with next Friday's date, 6 December 2024. As provided in the order, any further issues about the withdrawal of treatment should be referred to Arbuthnot J.

LORD JUSTICE PHILLIPS

59. I agree.