

Case No: COP20002405

IN THE COURT OF PROTECTION NEUTRAL CITATION NUMBER: [2024] EWCOP 68

<u>Royal Courts of Justice</u> Strand, London, WC2A 2LL

Date: 11th November 2024

Before:

MRS JUSTICE ARBUTHNOT

Between

KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

Applicant

-and-

XY (by her litigation friend, the Official Solicitor)

1st Respondent

-and-

XZ

2nd Respondent

Michael Mylonas KC (instructed by Ms Kiran Bhogal, Hill Dickinson) for the Applicant Sophia Roper KC (instructed by The Official Solicitor) for the 1st Respondent Parishil Patel KC (instructed by Miles & Partners) for the 2nd Respondent.

Hearing dates: 5^{th} and 6^{th} November 2024,

JUDGMENT

This Judgment was handed down on 11 November 2024

This judgment was delivered in public but the Transparency Order of Mr Justice Peel of 27 September 2024 remains in force, varied so as to provide that the 1st and 2nd Respondents shall be identified as XY and XZ respectively. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the parties, and treating clinicians, must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mrs Justice Arbuthnot:

Introduction

- 1. This is a tragic and difficult case. The application concerns XY who is known by all as X. She is an extremely popular, well-loved 54 year old lady who had a catastrophic cardiac arrest at home in the early hours of 6th May 2024.
- 2. XY has been in intensive care in King's College Hospital since that date first in a deep coma and for about the last four months in a prolonged disorder of consciousness. It is now more than six months since her cardiac arrest.

Application

- 3. The application made by Mr Mylonas KC on behalf of the King's College Hospital NHS Foundation Trust ("KCHFT") is for declarations, first, that XY lacks capacity to make decisions in connection with her medical care and treatment. All the parties agree this is the case.
- 4. The second declaration KCHFT seeks is that it is lawful and in XY's best interests for the life sustaining therapy and other therapy to be discontinued. KCHFT relies on the evidence of its witnesses Dr A and Professor Wade. KCHFT also relies on the second respondent's witness Dr Bell who had reached the same conclusions as the other medical witnesses.
- 5. The first respondent to the application is XY by her litigation friend the Official Solicitor who is represented by Miss Roper KC. With sadness, she supports the application.
- 6. The second respondent is XZ who is represented by Mr Patel KC. XZ is XY's adult daughter. She opposes the application. She has the support of XY's large and loving family as well as her friends. Many of the family and friends have attended this hearing.

- Mr Patel on behalf of XZ says that more time is needed for XY to recover from her brain injury. It is too soon to discontinue the therapy.
- 7. XZ and her family and friends, say they have seen changes in XY and their evidence is that she is responding to them when they visit. They contend that she is getting better gradually and this is shown by her following them with her eyes, blinking when they ask her to and squeezing their hands at times in response to their hand pressure as well as lifting her legs when asked to.

Background – the cardiac arrest

- 8. An awful feature of XY's cardiac arrest was that in the early hours of 6th May 2024, it was XY's teenage son, D, who found his mother after he had been woken by a strange sound. This was a shocking and deeply upsetting experience for him.
- 9. D had the presence of mind to immediately call 999, this was at 0034 hours. The ambulance arrived very rapidly, about ten minutes later. The paramedics started work on XY. I have no doubt they kept her alive. Had they not arrived and done what they did, she would have died that morning.
- 10. The paramedics remained at XY's home until 0148 hours. The paramedics did their best to restore her cardiac output by amongst other things giving her drugs until her arrival at the hospital at 02.15 hours. There was also at the same time difficulty in maintaining an airway. XY suffered kidney failure later which led to dialysis for a period.
- 11. There was about ten minutes between the cardiac arrest and the arrival of the ambulance. There was then a period of cardiac arrest for over an hour. For all this period, XY's brain was being deprived of oxygen. It was not in dispute between the parties that during this period of about one hour ten minutes XY had suffered hypoxic (lack of oxygen) brain damage.
- 12. XY has now been a patient in the Intensive Care Unit of King's College Hospital for six months. She is receiving life sustaining therapy and other treatment but sadly she is said to be in a prolonged disorder of consciousness.

Evidence

13. There was evidence from the family and friends of XY and the report of a visit by the agent of the Official Solicitor on 25th October 2024. I also had medical evidence. I have

not mentioned every piece of evidence I have read but I have taken it all into account when reaching my conclusions set below.

XY

- 14. During the hearing, particularly on the second day, I was fortunate enough to be told about XY.
- 15. XY was one of a large family (she has seven siblings and half-siblings) and is at the heart of the family and indeed the community. She is a Christian who attends church on Sundays and also during the week. She has many friends.
- 16. I heard evidence from the second respondent and three further witnesses who were family members. I read a number of statements and emails from others. 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.
- 17. The second respondent, XZ said her mother was her best friend. She used to speak to her every day and visited her most days before her cardiac arrest. She had visited her nearly every day since then. She had made sure that XY listens to the gospels and she reads her the scriptures.
- 18. XZ agreed her mother was a good cook with family and friends coming from far and wide to eat her food and enjoy her company. She spoke about the effect of her hospitalization on D. XY had been thrilled to have her son. They have an unbreakable bond. D did not want his mother to leave him. XZ described her brother as being in pieces.
- 19. She said XY knew she was there. XZ and the other witnesses described the signs that they had seen which showed them XY was getting better. XZ said she could feel XY knew she was there by the way she was using her hands to communicate. When she asks XY to blink she does so, and this has been happening since July or August. She said that more than once but not all the time, when she put her hand into her mother's and asks her to squeeze it she does.
- 20. The other witnesses confirmed this. B said that when XY heard his bass voice, she turned towards him. He also said he had seen her raise her leg when he had asked her to.

- He said the medication she receives makes her drowsy. Mrs C said that XY wanted to talk to her on Sunday and she saw her moving her lips.
- 21. Mrs E said she had seen XY responding to her children's voices. When her grandchildren touched her and asked her to squeeze their hands, sometimes she did it. She said she turns her head in the direction of sound. She said to her it seemed as if XY knew she was there.
- 22. XZ said that her mother was a fighter. She would choose life over death because she loved life. She said her mother would be upset if she gave up on her. She would have wanted her family to fight for her life. They have.
- 23. B is XY's younger half-brother. He said that he sees XY as his mother rather than a sister, after he had lost his mother in 2016. He was a truck driver and spoke to XY on Thursdays, Fridays and Saturdays, not earlier in the week because she was concerned that if he spoke on the hands free when he was working he would have an accident.
- 24. B spoke about her cooking and said she inspired him in the kitchen. She kept him on the straight and narrow and had never given him bad advice. Since 6th May 2024, he has been visiting XY frequently for up to three hours at a time. He described XY as a fighter and asked that she should be given a chance and be kept alive.
- 25. Another witness was Mrs C. She is XY's aunt and a real character. She gave a bright, vivid description of XY with much humour. She is very close to XY, she said she is more like a sister to her than a niece. They had gone to Jamaica together to visit friends and family in November 2023.
- 26. Mrs C said XY enjoyed baking, shopping, chatting in particular about the old days in Jamaica where Mrs C's mother who was XY's grandmother lived and was very strict. Mrs C described XY as beautiful in every way.
- 27. Mrs C wanted XY to be given more time. She said they would be happy to care for her, feed her, change her. They wanted her to be given a chance of there being a miracle. She said that XY's task had not finished, XY had plans for her life that had not been fulfilled.
- 28. Mrs E was not a relation but a friend of XZ 's who had known XY for 16 years. She used to see XY every month and would speak to her once every two weeks. She described XY as unwavering in her role as a mother and grandmother. She said she was compassionate

- and thoughtful in the way she prioritised the children and grandchildren. She wanted XY to continue to be part of the family's journey.
- 29. The respect and regard XY is held in is shown perhaps by a full court with reams of relations and friends. I had a number of other letters and statements which all described her as a fighter and a very popular lady.
- 30. XY is very close to her granddaughter F and she said she knew with all her heart that her grandmother would not want the doctors to turn off the life support. G, who is D's father, has his own health issues. He said that XY has been nothing but a great person to him and a loving mother to D. He said it had been difficult for D to cope with two parents being ill. H (XY's cousin) said she could reach out to XY and when H is in need she is always there for her.

Medical evidence

31. The family and friends of XY had said that she is showing signs of recovery. The medical evidence was at odds with the family's observations.

Dr A

- 32. I heard from Dr A, a consultant in intensive care, who had been treating XY at Kings College Hospital for six months. I also heard from Dr Wade a consultant in neurological rehabilitation who provided a second opinion and from Dr Bell who was an independent consultant in intensive care/anaesthesia instructed by the expert legal team representing XZ to give an independent view of XY's prognosis.
- 33. The treating consultant and the two experts (and indeed another second opinion expert Dr Ostermann) had all come to the same conclusion: on 6th May 2024, XY had no cardiac output or virtually none for over an hour. There were other complications because it was difficult to maintain an airway. She had suffered "generalised hypoxic brain damage" in other words brain damage caused by lack of oxygen.
- 34. She had renal failure when she got to Kings College Hospital. The experts agreed that this was an indication of the duration of the lack of oxygen. Another indicator of the severity of this was that the brain unusually was seen to be swollen when XY had a scan within 36 hours of her arrival.
- 35. When they gave their evidence, the treating consultant and the experts explained 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. In that situation other parts of the brain step in. So that in the case of a left arm affected by a stroke in part of the brain, a different part of the brain will step in to ensure the right arm does the work of the left one. This cannot happen when there is a generalised brain injury caused by lack of oxygen to the brain as had happened with XY.
- 36. Dr A explained that electroencephalographies (EEGs) had taken place to record the electrical activity in the brain. MRI scans had been done. The testing had shown that XY had gone from a deep coma into a more prolonged disorder of consciousness. This had different degrees. He said that XY was at the lower end of the spectrum.
- 37. The consultant described XY as having a sleep-wake cycle. She opens her eyes either spontaneously or in response to stimuli. This did not mean there was an improvement of her higher cerebral function. Dr A and the experts described these as spontaneous responses being driven by the brainstem.
- 38. Dr A said that although there had been a change from deep coma to a prolonged disorder of consciousness there was no reason to think that XY might move higher in the spectrum.
- 39. He said that for a number of reasons. First, the change out of the deep coma had happened in about the first month or so of her hospitalisation and there had been no further change in the clinical picture in the last four months.
- 40. Second, no further improvement was expected based on the investigations conducted, the EEGs and the CT and MRI scans. In a recent CT scan on 22nd October 2024, the brain was seen to be in a worse state than it had been before.

Dr Wade

- 41. Dr Wade, the expert brought in to give a second opinion to KCHFT, had assessed XY on 9th July 2024. His opinion then was that there was "overwhelming evidence of severe and extensive brain damage, there was no evidence of any significant awareness and her level of responsiveness was at a very low level".
- 42. Dr Wade said there was no evidence that XY could experience pain but as she was being exposed to painful things, the specialists should work on the basis that she might be experiencing pain and discomfort. The acute stage of her brain injury was over but there has been no significant improvement in neurological function. Her Glasgow Coma Scale

- has remained between 3/15 and 5/15. He explained in his oral evidence that the majority of recovery occurs in the first three months after a brain injury, with minimal change between three and six months and then no change after six months.
- 43. In his report Dr Wade described the difference between awareness and responsiveness. Every living being from an amoeba to man responds to their environment. An unconscious person continues to respond. Many of the responses are automatic including controlling blood pressure or the breathing rate.
- 44. He gave a helpful example of the sudden ringing of a telephone which would make one jump which was a startle reaction. Someone with awareness would reach out to pick up the telephone because they realize what the noise means and what they are looking at is a telephone. The person "generates a goal to reach out, pick it up and place it near the ear". That person recognizes the object is a telephone and not just a stone, for example.
- 45. Dr Wade saw a video produced by the family where they showed XY's eyes open. He considered that it showed automatic responses and spontaneous behaviours "commonly seen in unconscious people". In his oral evidence he said that there were no signs that XY knew whether her family members, friends or any others were there or not.
- 46. In his report and evidence he set out explicitly that XY would never be able to communicate her feelings, wishes or need for attention or interact socially even non-verbally with family and friends or have any "functional ability". This latter was particularly important to XY before 6th May 2024.
- 47. He gave what he termed was not "an evidence-based estimate of her life expectancy". He said it would be surprising if she lived as she was for 12 months but when he wrote his statement in July he thought it was more likely that XY would die in the next three months. As he made it clear, this was not based on evidence.
- 48. Dr Wade also pointed out that although the family wanted a "natural death" for XY, what was happening was that XY was being kept alive by mechanical intervention, such as tracheal suction, which was preventing a natural death.

Dr Bell

49. The family had described XY reacting to what was going on around her. Their expert, Dr Bell, considered this in his report and evidence.

- 50. Dr Bell, who had been a consultant in intensive care and anesthesia until very recently and continues his expert work, had been instructed by the solicitors representing XZ to give an independent opinion on XY's condition, prognosis and best interests.
- 51. He had read all the documents including the relevant parts of the electronic patient management system. He observed XY on 21st October 2024 when he also met family members including XZ. He assessed XY followed by a second assessment when the family members issued instructions to her, which were to show her responding to their requests. Dr Bell then interviewed the senior members of the nursing team and concluded with a discussion with XZ.
- 52. He had had 34 years of consultant experience in neuro-critical care. 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. He had been based in Leeds in a regional specialisation unit and the numbers of patients passing through intensive care there had been large.
- 53. In his thorough report he had explored XY's past medical history from about 2017 of COPD and dilated cardiomyopathy when she had an ejection fraction (the measure of the pumping efficiency of the heart) of 23%. This was very low. He had been told that there had been an unsuccessful attempt to site a pacemaker. XY had a heart attack during the operation and after that XZ said that her mother was too frightened of the risks of dying during the operation to try it again.
- 54. Dr Bell described XY as maintaining an unsupported blood pressure of 90/60. She received minimal assistance with her breathing (ventilatory support) and she needed very little respiratory physiotherapy input. XY is being fed successfully by nasogastric tube and her body mass remains the same as it was. There was no sign of any pressure ulcers.
- 55. He considered whether there was anything which could have skewed his assessment of XY's functions and concluded that her presentation on 21st October 2024 was "representative of her underlying condition".
- 56. Dr Bell set out the changes in XY's state. There had been progressive improvement in XY's breathing and cardiovascular status within two days of her admission. Seizure activity developed and this was controlled by antiepileptic medication. XY gradually

- recovered from the liver and kidney injury associated with the lack of oxygen and by 21st May 2024, dialysis and support was ceased.
- 57. XY was seen to be occasionally opening her eyes towards the end of May onwards but there was no evidence of her eyes fixing or tracking and no other evidence of responsiveness.
- 58. A family concern expressed by XZ and by B was that the drugs XY was on were masking her responsiveness. Dr Bell explained that although she was on antiepileptic drugs which can have a sedative effect, the dose she was taking would not hide her responsiveness.
- 59. In about June 2024 she developed a tongue injury due to her biting down on it during seizures. Eventually a bespoke mouth guard was created to prevent this and to allow the injury to heal although with a cleaning programme of three times a week when XY had to be anesthetized, this has been difficult to manage. I heard from Dr A that the cleaning is now carried out weekly.
- 60. On examination on 21st October 2024, Dr Bell said XY was neither asleep nor awake and her eyes opened and closed randomly with intervals of between five and 90 seconds. This was unconnected with any stimulation. When her eyes were open she blinked every three to five seconds. He did not observe her eyes fixing on or tracking any object. This was compatible with her significant hypoxic ischaemic brain injury.
- 61. XY did not move her eyes or head when her name was called or when she was asked to open or close them. He could not detect a response from her when there was a loud clap.
- 62. Dr Bell assessed her motor responsiveness. He tested her foot and found that when she moved it, it was not in response to a request, it was as he termed it a "spinally mediated reflex".
- 63. He then put pressure on her nail beds, where you would expect a response. XY gradually very slightly withdrew all four limbs and raised her head a little from the pillows. Nail bed pressure to her toes generated slight flexion of that particular leg but no other response. Pressure applied to the suborbital area (beneath the eye), generated tension in the body but no more movement in the eye.
- 64. The point was that this was unpleasant stimulation where one would have expected "facial features of discomfort" and there were none nor was there any change in XY's

- systems or functioning which was being monitored. In the tests he conducted he did not find any purposeful movement.
- 65. Dr Bell observed nursing care which included suctioning of the airways and did not see any discomfort in XY's expressions nor was he told by the nursing staff about any signs of pleasure shown to music or massage, or sadly even to the presence of the family.
- 66. Dr Bell was told that the manipulation of the mouth guard was the only intervention which caused changes to XY's heart rate and blood pressure but again there were no signs in her facial expressions that she was distressed or in pain. Dr Bell's view was that her reaction to the mouth manipulation was a brainstem reflex and was not a reflection that she was suffering pain.
- 67. Dr Bell watched for XY's responses to her family and there were none. There was no change to the pattern of eye-opening and blinking, nor did she squeeze XZ 's hand when asked to.
- 68. Dr Bell's conclusion was that XY was at the lowest point on the spectrum of prolonged disorders of consciousness, she had no awareness of herself or where she was. Until recently it would have been said of her that she was in a persistent vegetative state.
- 69. Dr Bell said XY's unresponsiveness accompanied by eye opening and a sleep-wake cycle was caused by the loss of the areas which were responsible for higher brain function.

 The brainstem which governs reflexes is more resilient to hypoxic ischaemic brain injury. He said that irreversible death of the neurons had occurred in all parts of the brain other than the brainstem.
- 70. Dr Bell explained that the brain had an extremely high oxygen requirement and was particularly vulnerable to the deprivation of oxygen such as had happened to XY on 6th May 2024. He compared the brain's requirements to the kidneys' and said the latter could withstand up to about an hour without a blood supply.
- 71. He said that the fact that XY had complete renal failure on 6th May 2024, indicated the depth, duration and severity of the hypoxia ischaemia on that date. The fact that the kidney recovered did not mean that the brain would as the latter had a "highly specialised nature of neuronal function".

- 72. Dr Bell also relied on the EEGs which showed no normal brain activity and the recent CT scan of 22nd October 2024 which showed a worsening position of increasing atrophy compared to the earlier scan.
- 73. Dr Bell's prognosis for XY was that she would remain at the low point of prolonged disorder of consciousness and she had "an extremely limited possibility of any progression to a minimally conscious state". Her survival is linked to the life-sustaining treatment she is receiving, including "maintenance of an artificial airway, ventilatory support when required and clinically assisted nutrition and hydration via the enteral route". She needs near continuous monitoring and observation.
- 74. As to the family's belief that XY's situation is getting better and that she is recovering and will recover, the professional witnesses all agreed that what the family is seeing are reflexes driven by the brainstem.
- 75. The professionals were clear, no recovery is possible. There may be change but XY will never recognise her family or friends. The professionals consider she does not know when her family is visiting. So far as pain and pleasure are concerned, there are no outward signs that she feels either.

Submissions

- 76. Mr Mylonas in submissions said medically it was a straightforward case, all the experts were agreed that there was no benefit in continuing treatment and it was in XY's best interests for it to be withdrawn.
- 77. He reflected the court's views when he said that although the medical evidence was all in one direction, it was the vivid picture drawn of XY which made it such a difficult case.
- 78. In terms of the law, Mr Mylonas relied in particular on the guidance given by Cobb J in *PL v Sutton CCH and others* [2017] EWCOP 22, in relation to an adult patient. Applying the guidance, he said it was clear that the court should make the declarations sought.
- 79. Mr Patel relied on the rich description given of XY by her family and friends. She was loved by family and friends including ones she had made when she had been working for the NHS. He was right when he described her as being the centre of each room she was in. She had considerable energy and she was passionate about cooking, shopping and chatting with friends and family. She loved life and lived it to the fullest.

- 80. Mr Patel accepted that all of this had been taken away when she had a cardiac arrest on 6th May 2024. The family accepted that she had been caused a very severe brain injury due to a lengthy time without circulation. It was so severe that her kidneys were damaged. This was unusual. Her kidneys had recovered because the cells in the kidney can regenerate.
- 81. As to her condition generally, the lack of pressure sores, the way that the unit had dealt with the tongue biting, Mr Patel accepted that this was thanks in no small part to the excellent care she had received.
- 82. The medical evidence is that of generalized brain death with no prospect of recovery. That is the bedrock to the application. The trust case is that the presumption in favour of measures sustaining her life is rebutted as there is no prospect of recovery. The family know that if the declarations are made that it is in XY's best interests for nutrition and endotracheal tube to be removed, then she will die.
- 83. Mr Patel agreed with Mr Mylonas that the court should apply the guidance given by Cobb J in *PL v Sutton CCH* to XY specifically. The court should be making a factual enquiry about XY herself.
- 84. In relation to XY's awareness of those around her, Mr Patel 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 XY would choose life in these circumstances.
- 85. Mr Patel concluded that it was not in XY's best interests to discontinue life sustaining measures, as he put it, at this time.
- 86. Miss Roper for XY, by her litigation friend the Official Solicitor, agreed that XY was an exceptional woman. She recognized her joyful personality, a lady who was a good cook, who remains at the centre of her family, who is a loving and caring mother and grandmother.
- 87. In terms of the medical evidence, Miss Roper said the Official Solicitor accepted the full medical evidence. The family had seen her lifting of her feet, squeezing hands and

- blinking. There was no medical evidence to support that this indicated potential for recovery. Not just from the doctors that the court had heard evidence from but also for over six months, no doctor or nurse had noted purposeful movement despite observing and caring for XY every day.
- 88. Miss Roper relied on the evidence of Dr Bell who said that the severity of the brain damage is so great that XY cannot respond to a request, it would be "outside all accepted medical knowledge" if she did. Miss Roper pointed out that XY had never discussed her wishes about what should happen in these particular circumstances although her family believed that she would choose life over death and would be upset if they did not advocate for her.
- 89. The Official Solicitor had to accept the medical evidence that XY will remain in the state she is in until infection brings about her death. XY would have to remain in the critical care unit. A tracheostomy is not available because clinicians will not provide one, and it would not enable discharge from ICU in XY's case because the mouthguard cleaning has to take place via sedation and that has to be done on a critical care ward.
- 90. Miss Roper finished her submissions with the comment that if the court ceased the medical intervention halting the process of death, nature would take its course and would determine her time of death. That was in her best interests.

Law

- 91. The parties provided an agreed document called Legal Framework Best Interests.
- 92. I do not refer to it in full. The parties are agreed that XY lacks capacity to make decisions about her personal welfare including refusing consent to the continuation of treatment provided by the hospital. In view of the disagreement between the family and the medical professionals it is for the court to decide best interests.
- 93. In relation to best interests, I am concerned in particular with section 4 of the Mental Capacity Act 2005 ("MCA").
- 94. Section 15(1)(c) provides for a declaration to be made by the court as to the lawfulness or otherwise of any act done or yet to be done in relation to XY.
- 95. The legal principles concerning the withdrawal of life-sustaining treatment were set out by Baroness Hale in the case of *Aintree University Hospital NHS Foundation Trust v*

James [2013] UKSC 67, [2014] AC 591. This was a case involving an adult patient receiving clinically assisted nutrition and hydration.

96. At paragraph 22, Baroness Hale said:

"Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

97. At paragraph 39, Baroness Hale continued:

"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 towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

98. Further guidance drawn from authorities is the following:

- a. The word treatment includes the clinically assisted nutrition and hydration that XY is receiving in the critical care ward.
- b. It is also important for a court to bear in mind that neither XY, nor her family nor indeed a court can make a doctor give any particular treatment.
- c. The court is to consider matters from the XY's point of view when considering wishes and feelings but we "cannot always have what we want" (paragraph 45 of *Aintree v James*). But so far as it is possible to find out XY's wishes and feelings, her beliefs and values or things that are important to her, it is that that should be taken into account by the court.
- d. The nature of XY's condition should be considered and the likelihood of her regaining capacity and the timescale for that.

- e. The importance of an actual diagnosis has reduced over time. When assessing best interests, it is the information relating to XY's condition and her prospects for recovery, it is the level of certainty with which these can be assessed that matters.
- f. 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.
- g. The value of human life is fully recognized, and it has sanctity. This strong presumption can be displaced by evidence that it would be contrary to XY's best interests to continue receiving life sustaining treatment. Every case is unique and is to be decided on its own facts.
- 99. I was grateful to counsel for setting out the professional guidance in this situation. This includes guidance from the Royal College of Physicians, the BMA, RCP and GMC.
- 100. A helpful decision that brings the principles to be applied together in a case such as this one was made by Cobb J in *PL v Sutton* (above).
- 101. I apply these principles to the decision I make below.

Discussion

- 102. First, lack of capacity, it is not in doubt that XY lacks the mental capacity to make a decision about the continuation of clinically assisted nutrition and hydration. There is no prospect of her regaining the capacity to make that decision.
- 103. Next, best interests.
- 104. XY's current condition. 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 6th 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 22nd 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 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. Purposeful movement would have to be consistent, unambiguous and observed on several occasions. This is not what has been happening with XY.
- 110. The next question is whether it is in XY's best interests for clinically assisted nutrition and hydration to continue to be delivered.
- 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 XZ, 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.
- 115. I note too that a decision that it is not in XY's best interests for the treatment to continue does not mean necessarily that she will die immediately, she may do so or she may not.
- 116. I put in the balance the quality of XY's life currently. There is no evidence from any family member or from any medical professional that after six months of prolonged disorder of consciousness she feels any enjoyment. She cannot smile or laugh, things she did in abundance before 6th May 2024.
- 117. Her family and friends visit her daily but she gets no enjoyment from their frequent visits. The evidence shows she does not hear her family when they visit or even knows they are there. XY used to get great fulfillment from her family life. She is at the centre of a large family and has many friends. She enjoys cooking and baking in particular. She enjoys shopping particularly at Zara, but that enjoyment has gone. Even if it was not clear before then, the latest CT scan of XY's brain conducted on 22nd October 2024, with increasing atrophy, shows her enjoyment will never return.
- 118. The answer to the question of whether she suffers pain or distress is neutral. When painful stimuli are applied XY does not react in a purposeful way although her heart rate does increase when her mouthguard is being manipulated. On two occasions tears were seen in her eyes. I cannot find that her current situation causes her distress or pain. It is not the case that she appears to require any pain control medication.
- 119. In the absence of any evidence of enjoyment or distress, I find the quality of XY's current life to be poor.
- 120. The next question is as to XY's prognosis if clinically assisted nutrition and hydration is continued. There is no real prospect of recovery of any of her functions. Her latest CT scan of her brain conducted on 22nd October 2024 showed a deteriorating situation with essentially a shrinking brain. This was demonstrably worse than the original scans in May 2024. A deteriorating brain will not result in an improved prognosis. I find the continuation of clinically assisted nutrition and hydration will not change this prognosis.

- 121. I am to consider next, the prognosis for XY if clinically assisted nutrition and hydration were to be discontinued. King's College Hospital has prepared a palliative care plan were the court to agree to discontinue the assisted nutrition and hydration. It would be withdrawn and the enteral feed would cease. The nasogastric tube would be withdrawn gently. The endotracheal tube would be removed via the mouth. The use of external devices to monitor XY would cease and they would be removed.
- 122. Medications would be stopped except the ones to control symptoms of pain and distress.

 The medical staff would ensure that any pain XY suffers is treated quickly. The care plan says it is not possible to say whether she would die rapidly or live longer.
- 123. If XY does continue living then discussions would take place with the family about where she should go to. This might include her home. The hospital palliative care service would be involved before the steps set out in the plan were started and they would support XY and her family throughout.
- 124. I have heard about XY's family's views and their wishes. XY was 54 years old when she had the cardiac arrest and by rights she should have many more years of life. She should be around to see her son D grow up and perhaps have a family of his own. She should continue to be an amazing support and inspiration to all of her family. She has grandchildren and in the natural course of things they will have children who she would be a loving and delightful grandmother to. The 6th May 2024 cardiac arrest came as a terrible shock to the family.
- 125. 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.
- 126. They believe that some form of recovery has taken place and that further recovery might take place. They have faith and believe a miracle is possible. I understand how it must seem to a family who see a change in XY from being on dialysis and then not; from breathing on a ventilator full time to needing it just occasionally, who has moved from occasional eye opening to more eye opening and movement and a sleep-wake cycle.

- Unfortunately, the medical experts, with all their expertise of catastrophically brain damaged patients, say these are changes but not signs of recovery.
- 127. 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. They have visited every day, they have played her music, they have chatted to her, they have noted any change in her presentation and believe that there has been improvement.
- 128. The doctors and nurses have been caring for XY for six months in the intensive care unit. They have ensured that she is fed and medicated appropriately, that her tongue is protected by a specially made mouthguard. They have turned her regularly to the extent that she has no pressure sores. They have clearly welcomed the family's involvement and kept them informed of their plans with regular meetings.
- 129. The hospital has also ensured that second opinions have been obtained and even third opinions. All the specialists that have been consulted agree that there is no recovery from the severity of the initial cardiac arrest with no or little circulation for over an hour.
- 130. I cannot see how the hospital could have done more for XY and her family in the circumstances. XY has been very well cared for in what seems to me to be an excellent intensive care unit
- 131. Finally, I consider the sanctity of life and XY's right to life under the European Convention on Human Rights. She has a right to life but I have to consider whether a decision to discontinue clinically assisted nutrition and hydration is proportionate and necessary in her particular circumstances.
- 132. 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.

Conclusion

- 133. I have taken the evidence into account. There are only two options for XY's care. The first is to continue with her life sustaining treatment or the second is to withdraw this and follow the palliative care pathway.
- 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.
- 137. That is my judgment.