Neutral Citation Number: [2021] EWCOP 64

Case No: COP13783897

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 13/12/2021

Before:

MRS JUSTICE THEIS

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Between:

CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	**Applicant**
- and -	
AH **(By Her Litigation Friend, The OS)**	**1st Respondent**
- and -	
A, M, S, K and T	**2nd – 6th Respondents**

- -

Miss Katie Gollop Q.C (instructed by **Kennedys Law**) for the **Applicant**
Miss Nageena Khalique Q.C (instructed by **Official Solicitor**) for the **1st Respondent**
Mr Simon Miller & Ms Martha Gray (instructed by **Simon Bruce, Dads House Law Clinic) all acting Pro Bono** for the **2nd – 6th Respondents**

Hearing dates: 7th & 8th December 2021
Judgment: 13th December 2021

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Approved Judgment

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MRS JUSTICE THEIS

This judgment was delivered in public. The judge has given leave for this version of the judgment to be published. The anonymity of AH and members of her family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Theis DBE:

Introduction

1. This matter concerns AH, 56 years, who has been a patient at Addenbrooke's Hospital, Cambridge ('the Trust') since the end of December 2020. She was admitted on an emergency basis suffering from severe symptoms of Covid-19. She has remained there since then and is currently an in-patient on the critical care ward, which is part of the Intensive Care Unit ('ICU'). AH has been on mechanical ventilatory support and treatment since January 2021. Her communication is mainly limited to movement of the eyes and head.

2. AH has four children A, M, S and K which the evidence demonstrates were the centre of her life, and have remained so since she has been in hospital. They are each, in their own individual ways, devoted to AH and have been dedicated to doing all they can to support her. There can be little doubt that they, together with the wider family represented by AH's sister, T, who is a party to these proceedings, have done all they can, as they expressed in their oral evidence, to *'fight for her'*.

3. AH's children and her sister, T, gave powerful and compelling evidence during this hearing. They have each, for very understandable reasons, found it very hard to face the reality of the medical evidence about AH's prognosis. That is completely understandable as they, like so many others, wish the position was different. Prior to December 2020, although AH had some underlying health problems, she was leading a happy and fulfilling life. No one anticipated the situation the family are now in.

4. The application is made by the Trust, who seek a declaration that it is no longer in AH's best interests to receive ventilatory support and treatment.

5. These proceedings were commenced in June 2021. Following a three day hearing before Hayden J, Vice President of the Court of Protection, in August 2021, he gave a judgment on 3 September 2021 granting the application but giving sufficient time for one of the children, S, who lived in Australia, to travel here so she could see her mother. The family appealed the decision. On 25 November 2021, the appeal was allowed, limited to procedural fairness around the circumstances of Hayden J visiting AH. All other grounds were dismissed. The Court of Appeal ordered the matter was remitted for re-hearing. The case was listed before me for directions on 29 November 2021. I heard oral evidence over two days on 7 and 8 December:

    (1) On behalf of the Trust from Dr A (Consultant Intensivist), Dr B (Consultant Neurologist) and Nurse C (Matron of Adult Critical Care).

    (2) Dr Danbury (Consultant Intensive Care Physician) the expert instructed on behalf of the Official Solicitor.

    (3) All of AH's children A, M, S and K and AH's sister, T.

6. The family have had the enormous benefit of pro bono legal representation through Simon Miller, Martha Gray and their instructing solicitor, Simon Bruce. Their advice and support has clearly been invaluable in this difficult case.

Relevant background and updating evidence

7. The background to this application is set out in considerable detail in Hayden J's judgment [2021] EWCOP 51, and was succinctly summarised in the judgment in the Court of Appeal [2021] EWCA Civ 1768.

8. As there is now no issue regarding the medical background, it is only necessary for the purposes of this judgment to give a summary. The issues in this hearing have centred on the medical prognosis and what the family have described are changes in how AH has reacted and communicated to them in recent months.

9. AH was admitted to hospital at the end of December 2020 and was diagnosed as suffering from Covid-19.

10. In January 2021 AH developed a systemic inflammatory response syndrome ('SIRS'), a recognised complication of Covid-19, with hyperpyrexia and multi organ failure. AH required renal dialysis, ventilation and sedation. This caused devastating damage. The episode was described by the clinicians as a *'cytokine/autoimmune storm'* and resulted in a number of profound and permanent neurological and myopathic conditions, namely cerebral encephalopathy, brainstem encephalopathy, motor neuronopathy and necrotising myopathy. In lay terms, AH suffered extensive and devastating damage to her nerves, muscles and brain as a consequence she is paralysed from the neck down, is unable to speak, is tube fed, doubly incontinent and has been on mechanical ventilation since early January 2021.

11. By June 2021 AH's clinical team considered it was no longer in AH's best interests to receive ventilatory support and treatment. As Hayden J noted, in early May, Dr A, the lead consultant for the Neurosciences and Trauma Critical Care Unit, wrote an email to colleagues raising the issue about whether they were acting in AH's best interests, a concern he shared.

12. From this time, it signalled a realisation within AH's clinical team that the slight improvement that had been noticed at that time came with a visible and marked increase in her distress. This prompted consideration of the burdens and benefits of treatment and a critical evaluation of where AH's best interests lie in accordance with the Guidance issued by the Royal College of Physicians and the BMA. Dr A proposed a meeting with the family, which was the start of many meetings that followed. The most recent having taken place in late October 2021.

13. In his judgment, Hayden J observed at paragraph 50 *'The timely identification of mandatory ventilation and organ support as inimical to AH's welfare and the recognition of its futility, is exquisitely balanced by the careful professional interdisciplinary analysis that all treatment was not yet futile, and that care should not be withdrawn. Some family members have been highly critical of the hospital. At times, some of their behaviour has fallen below that which the nursing and medical staff should be expected to tolerate. The kindness and patient perseverance of the response is consummately professional. The medical team have recognised the behaviour as a facet of grief, as do I. This of course does not excuse it. I am left with a striking impression of a clinical team which has aspired to and achieved, for their patient, the very highest level of medical care. I also note that this has been accomplished in an*

extremely busy hospital at the height of a pandemic public health crisis. It requires to be identified for what it is, inspirational.

14. On 18 June 2021, a referral was made to the Clinical Ethics Advisory Group concerning continued medical treatment in view of the distress that AH was reported to be regularly experienced by AH. Following advice from that Group, the Trust decided to make this application.

15. On 24 June 2021, it was confirmed that cardiopulmonary resuscitation would not be offered, and that her critical care support would not be increased from its current level. All family members agreed with that.

16. During further assessments in July 202,1 both Drs A and B noted AH's increased distress, she had no recall, was able to answer simple questions but struggled with more complex questions. Dr B observed she was *'suffering and distressed'.* This was agreed by the entire clinical team and the family but the visible distress is, as Hayden J observed, *'punctured by occasional shafts of happiness, such as when AH sees her family.'*

17. In his updating statement, Dr A set out events since September stating '*during the period since September 2021 until the end of November 2021 there has been a decline in AH's clinical condition and neurological function. In other respects, her condition is stable'.* He described the decline as taking the form of her *'wakefulness being less marked and occurs over a shorter duration and she is more easily fatigued.'* When she is awake he describes her being *'obviously and almost continuously* distressed' and that this is a '*ubiquitous feature of her clinical examination'* regardless of who conducts it. In his view, she cannot be cared for out of an intensive care unit.

18. He considered she continued to lack capacity. He had viewed the videos submitted by the family and recognised the difficulties in assessing patients who cannot communicate effectively, with the risks of over interpreting facial movement as meaningful responses. He recognises AH is smiling in response to her family, and observes it could be in mimicry or because she had heard the words like 'smile' or 'happy'. He had not observed her to smile spontaneously.

19. Dr A assesses AH's state of consciousness as being close to MCS+, at her best. This is a state of wakefulness with minimal awareness although in his view she does not meet some of the definition of MCS+ which is where *'Patients show – some evidence of language processing/communication such as following simple commands, intelligible verbalisation or intentional communication, albeit still inconsistently'* (Prolonged Disorders of Consciousness (PDOC) Guidelines page 30). The Guidelines also refer to evidence of a feature of MCS+ as *'evidence of reasoning/problem solving (either verbal or non-verbal)'.* Dr A states he has never seen this and states it is conceivable that her global neurology or neurological state is less than had been believed and there is the risk that they may be erroneously attributing a higher level of function to her facial movements, which may simply be mimicry.

20. In his updating statement, Dr A says such rigid definitions can be unhelpful and the experience of all the clinicians caring for AH consider *'she exists in a variable state of profoundly impaired consciousness, with minimal comprehension, almost no recall and frequent distress. This is associated with devastating and permanent physical*

disabilities which both confound her neurological assessment but also contribute to the helplessness and immensely upsetting state of existence.'

21. Dr A states he is certain that she does not meet the criteria to describe her state as emerged, nor does he believe that she plateaued at this state of consciousness. He relies on the clinical observations about how AH responds to questions when her answers are inconsistent and frequently incorrect. As he sets out, they have had the opportunity to observe AH over many months and, in his view, it is highly unlikely that she will progress beyond her current neurological state and the decline he has observed will continue. This, he sets out, accords with the conclusion reached by Professor Wade in his report dated 8 July 2021.

22. He notes that even if there was any improvement in AH, which he considered unlikely, she is likely to become increasingly distressed. The PDOC Guidelines cautions that an increase in awareness may not necessarily be equated with an improvement in the patient's quality of life.

23. In his careful oral evidence, Dr A recognised the richness of AH's relationship with her family but in his view, that did not materially impact on his assessment of AH's decision making and capacity. He described what the family are going through as *'heart-breaking'*. He has examined AH a number of times, as have the members of the team that care for her. Through that, he said they had *'a large body of knowledge*.' He said he *'completely accepts the family don't see the clinical situation as I see it. Just because the family disagree doesn't mean it is wrong.'* He acknowledges the family believe there have been improvements. He said he takes into account their views but also has regard to the trajectory of the illness, supported by an enormous body of expertise. He was asked why he had not asked AH about what she wants to happen, he responded that he does not consider she has the capacity to answer such a question and was concerned that it may cause her distress.

24. He raised the issue about what is reported when AH smiles and whether it is from genuine pleasure or comfort, or for another reason (such as mimicry), although he recognises that is not what the family believe.

25. In his updating statement, Dr B set out in detail the consequences of each of the neurological sequelae AH developed following the Covid – 19 related SIRS, namely necrotising myopathy, motor neuropathy, a brainstem encephalopathy and cerebral encephalopathy. Dr B, like Dr A, has been involved in AH's care since January 2021. In his analysis of the brainstem encephalopathy, he cautions about reliance on AH sticking out her tongue as a means of communication stating *'I believe that reliance on sticking out the tongue may sometimes cause confusion in the communication, as the family sometimes encourage AH to make this movement to indicate yes. Her tendency to this action is involuntarily, together with the frequency with which she is requested to do this voluntarily and her perseveration in this task raises uncertainty as to whether she is actually saying yes.'* He also notes the way any question is phrased can be important. For example, a question asking AH that if she would want to watch a particular television programme to *'stick out her tongue'*, it is unclear to Dr B whether she is answering the question or responding to the instruction at the end of the question. As he notes the uncertainty is further compounded because she frequently sticks out her tongue involuntarily.

26. In his statement, Dr B states his view that *'AH only survived the severe COVID related SIRS she suffered in early January because of the exceptional medical care she received from the doctors looking after her at that time. She has only survived to now because of the phenomenal nursing and paramedical care she has received and continues to receive. Patients who are paralysed and ventilator dependent are at significant risk of medical complications related to immobility, such as pressure sores and ventilator-acquired pneumonia. The risk of these complications is reduced by nursing and paramedical care but they cannot be prevented. The fact that AH has now been ventilated for a total of 334 days (just over 8000 hours) without developing such complications is an undeniable testament of the quality of care she has received. The professionalism, care, compassion and kindness shown to AH and her family by the bedside NCCU nursing, paramedical and medical staff is humbling and inspiring'.*

27. Dr B describes in his statement the extensive additional consideration AH's position has received not only from clinicians within the hospital but also more widely, as AH's circumstances have been discussed in wider medical forums, often with experts from around the world.

28. In Dr B's opinion, the neurological injuries sustained by AH are most likely para-infectious, i.e. are the result of the COVID related SIRS she developed in early January 2021, rather than direct viral infection or post-infectious autoimmune reactions triggered by her Covid-19.

29. In his updating statement, Dr B sets out the background to the completion of the ReSPECT form that was set out in Hayden J's judgment. The Court of Appeal dismissed the appeal that the form was evidence she would want to continue to be ventilated further in her current condition. The entry in the ReSPECT form on 29 December 2021 recorded 'full escalation and CPR'. As Dr B notes on 31 December 2021, both AH and the family were actively against ventilation. However, as this was an emergency situation and AH did not have capacity at that time, the doctors followed the ReSPECT form and undertook 'full escalation' in line with her stated wish on admission in a capacitous state. As he notes, this is exactly what the ReSPECT form is for. In his view, there can be no doubt AH would have died if the doctors had not acted against the wishes of some family members and ventilated AH. The form was updated on 24 June 2021 after discussion with the family.

30. In Dr B's view, there has not been any meaningful change in AH's neurological or clinical condition since the hearing in August. In recent weeks, AH seems to be more often tired and she has less reliable nodding movements, perhaps indicating a not unanticipated decline. She spends a lot of the time sleeping if left unstimulated. He considers there is a notable correlation between her level of consciousness and her level of distress. For most of her waking hours, AH is crying and distressed. Her distress increases when she needs intervention such as cleaning after being incontinent, suctioning to clear her airways, or re-positioning to prevent bedsores. In his opinion, AH is *'somewhere on the upper margins of MCS+ in the hinterland of having emerged, at other times she is closer to MCS-. She clearly recognises family members, and most of the time, but not always, is less distressed in their presence. She is fairly, but not completely, reliable in answering autobiographical and situational questions. She recognises objects, tracks visually, and reliably follows one step commands. However, she is rarely able convincingly to follow multi-step commands and does not seem to retain new information for more than a brief time. On most occasions, but not always,*

I think she recognises me. She generally makes good eye contact and connection but frequently needs to be re-engaged during assessments. She is unable to initiate any form of questions and does not seem to attempt to do this. There is no doubt in my mind that AH is self-aware and experiences the world. However, given the difficulties inherent in communicating entirely through direct binary questions, which will necessarily be right 50% of the time just by chance, it is often impossible to know if she is making an intended and meaningful choice or even giving a considered answer.' Her involuntary movements of the face and mouth, tongue and head further confound communication.

31. Dr B describes in his statement the necessary consequences of AH's condition and what care is required, such as regular suctioning, the consequences of desaturation and the personal care consequent on her incontinence. AH has no autonomy whatsoever, is entirely dependent on others for all aspects of her life and care and is unable to ask for anything, initiate any change or exert any control over any part of her environment.

32. Dr B agrees with the assessment that AH lacks capacity. As he described, at most she might have capacity to make a straightforward decision (such as to have her hair brushed) but he notes that whatever answer AH gives although plausible it is impossible to determine if the answer is considered, impulsive, cued or accidental. He is clear she does not have the capacity to make relevant medical decisions.

33. In his updating statement, Dr B sets out that he has carefully considered the updating statements and videos provided by the family. He refutes any suggestion that AH has shown distress as a result of unnoticed or neglected incontinence other than, possibly, an extremely rare event. He makes the same point in relation to turning that if there was any delay, it is extremely rare and needs to be seen in the context of the 334 days AH has been ventilated during which she will have been turned over 2,000 times. It was caused by extreme staffing issues, there were no adverse consequences and the senior nurses have apologised to the family. He makes it clear in his view that he has never seen anything other than *'compassionate, kind and expert care provided by the NCCU staff, despite the overwhelming pressure they have all endured during the pandemic.'* Dr B rejects the suggestion in A's statement that questions the motives or actions of the Trust. He sets out that in multiple meetings with the family the clinicians have sought to explain their moral, ethical and legal duties to AH, including issues about her capacity and what is in her best interests. As he notes, *'we have held many family meetings, during which members of the family have expressed differing and changing views about this question. A has been the most steadfast in his view that he wants ventilation to continue, and in line with these requests ventilation has been continued for 11 months. The medical team came to the court because we could not establish AH best interests with confidence.'*

34. Dr B states that in their statements each describe how AH has become more aware since April this year, as she is able to answer simple situation and autobiographical questions much of the time. However, in his view, this upward trajectory apparent in the spring and early summer has not been sustained. AH's level of awareness has plateaued and some of the clinical team consider it has deteriorated, for example in the Speech and Language reports.

35. In his thoughtful and deeply reflective oral evidence, Dr B maintained what was set out in his written evidence. He recognised that when the family are there, the level of

distress is reduced but there are significant periods when they are not there. He described AH's life as extremely challenging, how the long term memory is the last thing to go and, as a consequence, he is not surprised AH shows some recognition of her family, as they represent a deep memory. He considered her decline has been caused by exhaustion. As regards AH's communication, he said it is very easy to inadvertently give cues to someone. He was asked about the improvements and changes the family have observed, he said *'I have spent a lot of time thinking about this. AH is a much loved central person, the thought of losing her is unbearable. What this family has been through is unspeakable, they still hope each day, it is difficult and distressing, family want her to get better…they have a profound desire for her to get better...it is difficult for them to come to terms with this and seek to blame the hospital as displacing responsibility, they have to fight for their mother.'*

36. In her updating statement, Nurse C confirmed she has overseen AH's care since January 2021. This includes undertaking direct nursing care. She describes in her statement that a bespoke, exceptional visiting plan has been arranged for AH. All other critical care patients have one named visitor for one hour a day. After planning for end of life care during August and September the Trust lifted all restrictions on who could visit AH, allowing wider family to visit and say their goodbyes. Running alongside that AH has seven named visitors who are able to visit in pairs for two hours, twice a day. The clinical team have been flexible about the times of these visits and they recognise that seeing close family, who AH recognises, is important and comforting for her.

37. In her statement she sets out that the nursing team consider AH has become more subdued and tires more easily. She continues to intermittently cry and show distress both during examinations and routine care and also spontaneously when roused. She describes in the statement how the nursing team seek to communicate with AH, trying to explain what they are doing. She notes the difficulties and tensions there have been on occasions between the family and the nursing team and the need for arrangements to be put in place to seek to avoid such situations.

38. In her oral evidence she confirmed that AH spends increasing time asleep and can become distressed and tearful at random times during treatment, visits and when alone. She said the increased visiting regime for AH's family was because the hospital wished to be as compassionate as they were able to. If AH remains on mechanical ventilation that level of visiting could not be maintained. She confirmed she worked two clinical shifts every two weeks and is involved in AH's care. She was asked about whether the treatment is painful, she said they knew from other patients that suctioning is something they talk about as being very painful. She agreed that AH can respond to simple questions, but is not consistent. She had viewed the videos and agreed AH derives some pleasure from being with her family, although AH has at times been crying and distressed during such visits. She described what happens when AH is distressed as *'the anguish in her face like a scream, a silent scream, her eyes look frightened and scared, squints her eyes occasional tears but no sound'.*

39. Dr Danbury's updating report needs to be read with his earlier reports. He has reviewed the updating clinical records, the updating statements from the family and the videos they have provided and summarises his opinion as follows:

(1) AH lacks capacity to make a decision about long term mechanical ventilation.

(2) Sufficient time has passed to be certain about AH’s prognosis.

(3) On the strong balance of probabilities AH will not make any further physical improvement or any further cognitive improvement.

(4) AH is in terminal decline of consciousness and will either die following transition to palliative care, or will die of a sudden catastrophic event.

(5) AH requires suctioning of her trachea every 2 – 3 hours, regular cough assist and re-positioning every 4 hours. Other than an intensive care unit, there is no facility that can provide this level of support.

(6) The quality of care, both nursing and medical, delivered by the Neuro Critical Care Unit has been exemplary.

(7) Although it is the court’s decision, my opinion, which is no longer finely balanced, is that it is not in AH’s best interests to receive medical ventilation.

40. In his recent report he details the different descriptions given to what AH has suffered, whether it is SIRS or cytokine storm or cytokine release syndrome. Which it is Dr Danbury considers is immaterial. AH has suffered a severe reaction that, in his opinion, is related to an immunological response to the Covid-19 infection. It is his opinion that AH’s neuropathy (or neuronopathy as suggested by Dr B) and myopathy is untreatable and irreversible.

41. In his report, Dr Danbury considered the issue of capacity and concludes AH lacks capacity to make the decision the court is being asked to make on her behalf, and does not consider any further assessment is required. He describes the question about continued ventilation, including a number of persisting burdens which she needs to understand before coming to a decision, such as she will remain completely paralysed, will need to stay ventilated and remain in ICU, is doubly incontinent, tube fed, all her activities of daily living will need to be performed by others and has no prospect of leaving the ICU. In his view, AH does not have a functioning short term memory, although her long term memory enables her to recognise and interact with family members. She is unable to recall words she has been asked to remember by the clinical team, for even a few minutes. Dr Danbury considers AH is not able to weigh the benefits and disbenefits of continued mechanical ventilation on ICU.

42. Dr Danbury agrees with Dr B’s conclusions regarding AH’s physical condition, save for the term he uses to describe it. In relation to AH’s cognitive position, he refers to the fact that he was the only intensivist on the Guideline Development Group. He agrees with Dr A’s analysis, AH’s behaviours are consistent with either MCS- or MCS+. His opinion on the updating evidence, including the videos from the family, are that AH’s behaviours are more consistent with MCS- as she does not initiate conversation, is not able to use communication aids and does not return to a task when distracted. He considers she has not emerged from a minimally conscious state, it is debatable whether she is currently MCS+ or MCS-.

43. At the end of his report he states his opinion that AH will remain mechanically ventilated for the rest of her life; require the high level of treatment and care she is currently receiving and will never emerge from a Minimally Conscious State. He

considers AH is on the Terminal Decline of Consciousness, the timeframe for which is not clear. He recognises the family may not agree with him, but in his view he has not seen any objective evidence of improvement in her physical or cognitive function. He considers the process of her dying, if she remains on NCCU *'will take months and will be progressively more distressing for her, her family and her carers'.*

44. As regards the benefits of prolonged mechanical ventilation, he summarises them as follows: (i) Prolongation of life until a catastrophe occurs, which would be sudden, unexpected and unlikely to be with any opportunity for her family to get to ICU before she dies. (ii) It is consistent with what some of her family say regarding her wishes and preferences. (iii) It is consistent with what her family say are her religious beliefs, although Dr Danbury notes he has cared for patients where withdrawal of life sustaining treatment was not considered against Islamic beliefs by either the patient or families concerned. Dr Danbury recognises the evidence about her wishes and religious beliefs remains a relevant factor for the court to bear in mind.

45. The disbenefits of continued mechanical ventilation remain as he has outlined previously, save that his clear view now is that AH could not be cared for anywhere other than on ICU. Also, in his view, there is no further opportunity for any recovery.

46. In his sensitive oral evidence Dr Danbury said what is different now is that AH has spent more time on ICU, with the ability to assess her physical and cognitive function, which allows him to be more certain about the long term prognosis. He considers the chance of her emerging into a conscious state is *'very small indeed'*, later saying it was less than 1%. He did not consider his position was impeded by not having visited AH, as he considered all the records were internally consistent, whilst he was happy to see her he didn't believe his opinion would change. He had heard S's oral evidence. He considered AH is likely to respond to familiar voices and people as her long term memory is preserved, so he is *'not surprised'* that she smiles more to family and they get the best out of her. The family are looking for signs of improvement, he recognised the horrible position the family are in but did not consider S's evidence was inconsistent with what is in the notes and his view.

47. He agreed the family get the best out of AH, although observed a similar explanation for AH's reaction regarding S could be they were also upset, their body language understandably could be one of sorrow and upset, it was very difficult to say. He agreed AH was distressed, but it is difficult to understand the cause of it.

48. He was asked about some of the treatment procedures AH had to undergo. He said they rely on accounts of people who have survived periods in ICU who give accounts of the level of distress and discomfort caused by the treatment, likening suction to feeling like having a red hot poker and being a very unpleasant procedure.

49. He was asked about the clinical notes. From his extensive experience his view is that in ICU if you are not getting better, you are getting worse. The longer there the patient is less capable of responding to any new insult. He said it was difficult to give a time period, but AH's trajectory was a slow decline and ultimately she will die. He confirmed MCS is the lowest possible functioning of the brain.

50. If mechanical ventilation was withdrawn, he said AH's muscular system is very weak and whilst Dr A's knowledge was more up to date, he considered she would pass away

relatively quickly, as her muscles would not allow her to breath adequately. He described how it will be necessary to provide such treatment as is necessary to ease removal from mechanical ventilation. He considered there is a need to be proactive rather than reactive, the ICU have very great experience of these situations, due to the 20% mortality rate of those who are admitted to ICU.

51. In answer to questions from Mr Miller, he said he accepted the family are the people AH is most likely to respond to but, in his view, that does not necessarily mean AH is responding to what they are saying due to the impact of other considerations, such as body language. Talking is only a small part of communication, non-verbal communication is more than 50% of communication. Body language and posture are a critical part of communication. He said he would struggle to describe AH as stable, in his view she is in a slowly declining state.

52. In answer to questions from Miss Khalique Q.C. he described examples of what he meant by a catastrophic event, such as pulmonary embolism, a gastric intestinal bleed, or septic shock caused by an infection from a bed sore, the tracheostomy or the catheter. He said they could result in a horrible and sudden death. He considered the risks he had given are all dependent on the level of nursing care. In this case the fact that AH had been on ICU for 11 months without having significant issues, such as bed sores, is an indication of the very high standard of care she has received. He considered the reports from the family of changes they had seen in AH were consistent with MCS, as it is possible to have new behaviours but different patterns do not, in his view, equate with improvement.

53. Dr Danbury was asked what had changed to result is his opinion not being finely balanced, he said *'overall AH is suffering from necessary treatment that she needs to undergo to preserve her life, she doesn't understand why she needs treatments, she is existing rather than living. She gets pleasure from family but even if more visits no change to her overall experience which is slanted to being distressing interventions rather than pleasurable experience. Based on my experience…she has no prospect of leaving ICU and I think she will get less pleasure and have the continuing torment of the interventions.'*

54. The updating statements from the family set out and describe their recent time with AH, and include the evidence from S about the comparison she noted from when she last saw AH in April and then in October. That is not inconsistent with the improvements noted in June and July. In their own separate ways the family describe what they consider has been an overall improvement in AH, particularly in her ability to be able to communicate. The court has had the benefit of viewing the videos submitted showing times when they have been with AH, both before and since the August hearing.

55. In her statement M, who has probably spent the most time with her mother, states her present view is her mother is *'making small progress. I have witnessed her laughing and grinning when A [her brother] makes a joke with AH. You see she is responding to his joke with a pleasurable laugh.'* She describes how she has written questions on a whiteboard that she considers AH has answered. She is critical of some of the care given to AH. Her statement concludes as follows, setting out what she seeks from the court: *'(i) that my mother is given further time to continue her ongoing progress and spend more time with us as a family and extend her life support further; (ii) I seek that the court takes my mother's religious belief with greater weight as it is a central role*

in her life; (iii) to encourage the staff [at the Trust] caring for my mother to care for her as before to help her come to a full recovery' . As M sets out movingly at the end of her statement *'We as a family have not lost hope that our mother will continue to recover, and we know that our mother holds the same faith'*.

56. In her moving oral evidence, she gave an example of how taking more time to explain the treatment that were going to be undertaken reduced AH's distress. She agreed that she only asked her mother simple questions and gave her time to respond. M felt she could tell when AH is in pain. She said she *'wanted the best for her mother, if I could bring her home I would in a heartbeat, I accept she can't come home. I want her to have the best to the end.'* In answer to her questions her mother had wanted them to fight to the end, as M said *'she wants us four children to come together so we can all say we did everything for her'*.

57. In his statement, A sets out AH's background, the enormous difficulties she has overcome, the strength she has demonstrated to not only her children but also her wider family. The depth of feeling for her within her close and wider family is tangible. He describes how more recently, as the difficulties that had been such a part of her earlier life have subsided, religion has played a greater part in her life. He visits her in hospital as often as he can, describing in his statement how she is able to respond to his questions and to attract the attention of the nurses by turning her head. He is critical of some of the doctors and the actions they are taking. Since the last hearing he said AH's awareness has '*tightened up…she has come to terms with her condition and knows that the chances of becoming better are little, but this has not changed her mind on the continuation of the ventilator. She STILL wants to continue her life'*. Recent changes are described as being '*she laughs so much when I joke with her….she doesn't cry anywhere near like she did before, she is a much bubblier, happy, funny person and she may not be able to move but that doesn't mean she wants to stop living'*. He ends his statement with *'My mother should be given every chance to come home or attempt to be ween (sic) off the ventilator. We just want her with us and she wants to be with her family'*.

58. In his oral evidence A gave detailed accounts of how he communicates with AH, describing how she squints her eyes or sticks out her tongue. He described how he had asked her the question about withdrawing treatment and she is telling them to fight for her. He described how AH laughs, is cheeky and how they pray with her, describing her faith as everything to her, she is scared to die. He movingly outlined how she had fought for her children, saying *'if you knew her pre-Covid you would not voluntarily put her at end of life'*. Understandably, A found it difficult to answer the question raised by Dr Danbury's report that she may succumb to a catastrophic event and die without her family. He considered AH did have capacity to answer the question the court is being asked to determine. He described how he found the approach taken by Dr B easier than Dr A.

59. K describes in his statement the recent improvements he has noticed with AH, describing her as a lot more alert and now more aware than ever before. He described a recent visit when he went in and she kept smiling at him, he put his head against her and *'very strongly she was pushing her head against mine. It was emotional and said to see her trying'*. He says she has good and bad days but overall *'very positive. She is well aware of her condition and has said to me several times that she would want to continue fighting.'* He described a recent visit when he went to see AH and noticed she

was crying. He asked if she was in pain, she indicated no and he then asked if she was upset at the situation she was in, she responded to indicate yes. He reassured her not to worry and he continued *'I kept saying mum you will get better she would say No numerous times'*. He said this indicates to him she is fully aware of her condition. He continues in his statement *'I said mum don't worry over time you will get better, I promise you. I always remind her of this. She is a fighter and will not give up'*.

60. In his measured and careful oral evidence K described how AH's eyes lit up when she saw him. He said he asked her if she will get better and she responds no then starts crying. He often visits her early evening and they watch films together, which he said she selects. He feels she holds back her tears when he leaves and said *'more I see her the more I don't want to let her go'*. He feels certain AH would not want mechanical ventilation to be withdrawn, she would be guided by her religious beliefs, would not want the machine switched off as *'could be potential for improvement'*. He recognised AH had been given excellent care and asked the court to consider giving her more time.

61. In her statement, S describes what she has noticed as the difference from when she last saw AH, she considers she has become more aware and feels she has become more conscious. She produces the video of when she visited with her son and describes how AH was interacting with her grandson, who she has only met since she has been in ICU. She also describes AH's reaction when she told her mother about her recent miscarriage and how she considered AH understood what she was saying. She is also critical in her statement of the care that has been given to AH, expressing her concern about the lack of interaction with AH.

62. In her understandably emotional oral evidence, S described the difference she noticed from when she saw AH in April to her return at the end of October. AH's face was more responsive and her eyes open a lot more. She felt AH gave her clear answers, although recognised she had involuntary movement of the tongue. She described her responding with shaking her head when she asks if she is okay, and how she tries through a process of elimination to find out what is wrong. S described how she told AH about her recent miscarriage, describing how AH looked at her very hard as she was telling her and they both cried. She considers AH has a deeper understanding than just simple concepts. She described her mother's religion as being important to her, *'she doesn't want to give up…she gets joy from seeing us'*. She said her mother *'doesn't want to leave she needs to be given more of an opportunity'*. She felt her mother did have capacity and with her is able to follow two stage commands. In answer to the question if AH understood what is going on, her condition and the need to be ventilated would she chose to continue to be ventilated. S recognised that is a *'tough question – my mother wants a chance to get better'*. She acknowledged she didn't reject the medical evidence that there is no chance of AH getting better but said *'I know my mother would not want to go on palliative care'*.

63. In her statement AH's sister, T, describes how she considers AH has become more accepting of her condition. She outlined an occasion when she was present in April/May when Dr A described her condition to her and AH became very distressed and hysterical. At a more recent occasion at the end of October, T was present when Dr A spoke to AH and when he set out her condition she did not become distressed in the way she had previously. She describes how in the discussion afterwards she and Dr A interpreted AH's responses differently. When T went back to see AH she asked her *'do you want to live in this way and [AH] shook her head to say no. I then asked do you*

want to get better and she was able to nod her head. I feel [AH] has capacity to make decisions for herself on good days. When [AH] is not having a good day, her energy is focussed elsewhere and she struggles to answer clearly'. T describes how she helps AH pray and the emotions she observes during that, in particular AH slightly turning her head or moving her eyes from right to left to make her salaam (closing of the prayer). T also describes the comfort AH gets out of the religious routines they follow on Friday. T describes some occasions when AH can respond to something funny happening when AH *'scrunches up her face in laughter and becomes giggly'*, although she recognises this doesn't always happen. T concludes her statement *'When [AH] is content, I believe she has the capacity to guide us with what she wants. And as [AH] becomes more aware her capacity to answer simple to complex questions is developing'.*

64. In her thoughtful and reflective oral evidence, T described her sister, and the struggles she had overcome and how she is loved by all the family. She responded about what AH would say about the current situation saying *'my children are here they are all fighting for me'*. T described how each of AH's children have a different relationship with AH, underpinned by the strength of their love for her. She said the staff are *'exemplary'* and it is not their experience when they visit that she is continuously distressed. She feels they don't see the communication the family have, although she noted AH had slowed down. She said AH would want *'her four children with her when the time comes, without a shadow of a doubt'.*

Legal framework

65. AH's best interests are to be determined in accordance with s 4 Mental Capacity Act 2005 ('MCA 2005').

66. The Code of Practice states

> *5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.*
>
> *5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.*
>
> *5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is*

> *foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests.*

67. In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 Lady Hale set out the route map for how the court should approach the issue of best interests. The starting point is the strong presumption that it is in P's best interests to stay alive.

68. When considering what is in P's best interests each case is fact specific. Lady Hale set out in *Aintree* at paragraph 39 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 places 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'*

69. As to whether the treatment was overly burdensome Lady Hale endorsed the view that the burdens had to be weighed against the benefits of continued existence, and this assessment must take account of P's broader interests. This includes, for instance, their family lives and any preference they have expressed, Lady Hale observed 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 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 are 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'*

70. AH's rights protected by the European Convention on Human Rights are engaged, in particular Articles 2, 3 and 8 recognising the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (*Burke v UK* [2006] App 19807/06).

Submissions

71. Miss Gollop Q.C. asked the court to consider what she set out in paragraph 40 of the closing submissions on behalf of the Trust in August, namely

> *'There are two choices for [AH]. One is continued treatment on ITU until she succumbs to a fatal infection, on the ward, at an unpredictable time, when there may be no family in attendance. The other is that she moves to a calm, quiet and private place, where the close of her life in this world can come to pass when she is back where she has always wanted to be – at the heart of her family - surrounded by their love, in an atmosphere of prayerful peace and togetherness.'*

72. In her submission that choice remains the same, although Dr Danbury's evidence has modified that he now considers the case no longer finely balanced. She submits to refuse the application would expose AH to a lonely, painful death, probably without her family. She submitted the Covid-19 pandemic has been brutal, causing emotional brutality up and down the country. Dr B's evidence set out how unfair the position is, how someone at the heart of this family can be taken away by the virus, become worse and reduced to someone who has no power and is wholly dependent on others. Miss Gollop recognised the situation as being unbearable. Miss Gollop submits the coping strategy for the family is to continue fighting in the face of evidence that pointed the other way, and for some family members to criticise the care being given to AH.

73. Miss Gollop relies on the evidence of Dr Danbury, who is independent of the Trust and very experienced in this type of case. He gave clear evidence about the realities of life on mechanical ventilation. Professor Wade described in his report that AH was an extremely independent person who would not want to spend her life in an institution where there is no privacy and she is wholly dependent on others with no prospect of leaving. In her submission it is overwhelmingly in her best interests to be in a situation where she can be with her family which would accord with her wishes rather than face the alternative which would expose her to continued pain and distress and the prospect of an end of her life without her family.

74. Mr Miller and Ms Gray on behalf of the family set out that the family do not recognise AH as being lonely, isolated and distressed. He submits the evidence they gave points the other way through the undiluted care, love, affection and deep commitment they have shown towards AH.

75. Mr Miller stressed the evidence given by the family about communication and the way they described being able to communicate with AH, in particular S's evidence about seeing the change in AH and how she communicated with her and K's account of how AH pushed her head towards his. That powerful evidence has to be considered with the medical evidence. Mr Miller submits the evidence from the family should be given weight as they have the time that perhaps others on a busy ICU unit would not have. He relied on the way the evidence had been given by the family members and their careful insight over time.

76. Miss Khalique set out how the Official Solicitor's position had changed, the position in her submission is no longer finely balanced for the reasons given by Dr Danbury. The Official Solicitor distanced herself from dismissing the evidence from the family. They gave compelling evidence, particularly M who had spent so much time with AH. The Official Solicitor's previous position statement identified three core elements that the court would need to carefully weigh in the balance; AH's religious, cultural and family values. All remain, in her submission, powerful factors.

77. The Official Solicitor considers Dr Danbury's evidence is now of a different complexion, informed by four months of further observations of AH. He considers she will not get better and has increased risk of infection. AH now can only be cared for in an ICU. Some family members realistically recognise AH would not want to live this way where there is no prospect of her getting better or leaving the ICU. Finally. Dr Danbury is clear the trajectory is decline and death, but with no reliable timeframe. AH may live for months with mechanical ventilation but would have to endure the burdens that come with such continued treatment.

Discussion and decision

78. The court is faced with two irreconcilable positions.

79. The medical evidence is united that AH lacks capacity to make the decision the court is being asked to make and that her position is no longer finely balanced. She is not going to recover, needs to remain cared for in an ICU with mechanical ventilation, there will be no emergence from her current condition, she faces, if the medical evidence is accepted, a steady terminal decline to her inevitable death, with the increased risk of contracting an infection and experiencing a sudden, lonely and painful death. AH will remain wholly dependent on others for every aspect of her day to day living, the treatment that is necessary to continue her existence causes discomfort, pain and distress to AH and needs to be undertaken at very regular intervals, at least every 2 – 3 hours.

80. The family are united in their desire, as they describe it, to fight for AH until the end. That is wholly understandable, it avoids the difficult balancing exercise the court is required to undertake in determining what is in AH's best interests. AH is someone who has dedicated her life to others, in particular her children who she was utterly devoted to, as they are to her. She has overcome adversity and her deep love for her family, her mother, siblings, children and grandchildren shines through the evidence the court has. The oral evidence of her children and her sister were each different in the way they described how AH reacted to them and what their individual experience had been of how she communicated with them. My sense when listening carefully to their evidence was that some of them were more prepared for the reality of AH's position than others, whilst none of them wanted to depart from the unifying decision to fight for AH to the end, as they believe she would have wished. The evidence demonstrates that she derives and experiences love and comfort from their visits and the previous description of these visits as shafts of sunlight is entirely accurate. Particularly when compared to what AH has to endure in relation to her treatment to stay alive. AH's neurological condition means that she retains some long term memory and is able to recognise members of her family.

81. As Miss Khalique observed in her closing submissions the religious, cultural and family values which were each so important to AH need to be carefully weighed in the balance.

82. I agree with the evidence of Dr B and Dr Danbury, the position this family are in is unbearable. They simply do not want to give up on their hope that AH may make some recovery. That was a theme running through their oral evidence, it was deeply felt that there remained some hope that would be the case and they each referred to it in their evidence. Those feelings will have undoubtedly and understandably impacted on how

they interpreted the way they saw AH communicated with them. I do not doubt the accounts they have given, but they need to be seen in that light.

83. I accept the evidence from Dr B and Dr Danbury, that such communication can be interpreted in a number of ways and can be influenced by the way questions are phrased, and non-verbal communication, with the consequence that the interpretation given by the family may not be the only one that they sincerely wish it to be. There may be other equally plausible interpretations of the way AH has responded, such as the way the question is asked and mimicry. Due to her neurological impairment AH's ability to communicate is, in my judgment, much more complex than the way it is viewed by the family.

84. The court cannot ignore the extent of the other clinical evidence, the most recent medical records that are set out in Dr Danbury's updated report and the medical records bundle which demonstrate the wider evidential canvas the court needs to take into account that AH spends long periods sleeping, has periods of distress and finds the regular and invasive treatment that is necessary to sustain her life cause her discomfort and is distressing. As Dr Danbury observed, there is a consistency between the records from the various professionals that have involvement with AH, now over an extended period of time. It was the extent of the observations and the content of the records that Dr Danbury relied upon.

85. I accept Dr Danbury's detailed and carefully reasoned evidence, supported by his undoubted expertise and experience over many years as an intensivist. In his opinion, the accounts given by the family did not change his overall conclusions when he factored in AH's retention of her long term memory, recognition of her family and the issues he raised regarding over interpreting communication from someone with AH's cognitive difficulties. Whilst I don't doubt the sincerity of the evidence given by the family of the way they describe AH communicates with them, in my judgment they are bound to view it in a particular way due to their very strongly and deeply held wish for AH to show signs of some recovery, or change. That view, in my judgment, is contrary to all the other evidence in the case, that there is no prospect of AH recovering, which evidence I accept.

86. I also accept Dr Danbury's conclusions about the very high standard of care AH has received in hospital. The dedication of the clinical team that have been caring for her is clear and is demonstrated by the fact that despite the extended period of time AH has been on ICU, she has not succumbed to any infections.

87. I am satisfied that AH lacks capacity. As has been set out in the evidence, and is largely accepted by the family, she can only answer simple questions, her answers are not always consistent and she has limited, if any, short term memory. She simply would not be able to weigh up or even retain the relevant considerations involved in the nuanced and complex decision as to whether her treatment should be continued, or not. That conclusion regarding her capacity is underpinned by the evidence of Dr Danbury that she lacks such capacity and his review of the records, including the most recent capacity assessments.

88. Turning to the issue of best interests. In undertaking the balancing exercise the court must give weight to the values that AH holds close, namely her religious, cultural and family values. The important presumption that it is in AH's best interests to stay alive

needs to be viewed through the prism of these important components of her life. Prior to her admission to hospital the evidence demonstrates her faith, her cultural values and her family were each an integral part of her life. Her family have given powerful evidence about how they have continued her Muslim faith with her since she has been in hospital, detailing how they pray with her and support that with music which she finds comforting. Her family have remained wholly dedicated to her, visiting her at every opportunity they are able to and doing all they can to make her life as comfortable as they can. AH experiences some pleasure from such visits, which through her long term memory she is able to recognise the familiarity of her family. However, it needs to be recognised that the frequency of such visits are likely to have to be reduced if she remains on long term mechanical ventilation, due to the risk to others caused by the health restrictions and the lack of parity regarding visitors with other patients in the ICU.

89. By remaining on mechanical ventilation AH's life would be prolonged, it would accord with the religious beliefs she holds and practices, would be consistent with what some of her family say her wishes and preferences would be and she would continue to see and have the pleasure of continuing visits from the family, albeit they are likely to be reduced.

90. Against those benefits are the burdens of the continuing treatment. Dr Danbury's evidence was balanced and compelling as to the realities of what life is like on mechanical ventilation on an ICU. The detail he gave was from those who had been the recipient of such treatment and, when recovered, had been able to give an account of what such treatment had been like. It was described by him from these accounts to be disorientating, noisy and at times extremely painful and uncomfortable, particularly in relation to suctioning which is a process that AH is having to endure every 2 – 3 hours. The extent and frequency of this suctioning means she will not be able to be cared for away from an ICU. Dr Danbury's evidence was clear, there is no realistic prospect of any improvement in her physical or cognitive functioning. In addition, AH is having to endure the other aspects of her life such as the four hourly turns, being doubly incontinent, never being able to eat or drink and will never emerge from an MCS. Whilst not diminishing the evidence given by the family, the clinical records provide a wider and more detailed account of the distress she exhibits during the regular and frequent interventions that are necessary to keep her alive and also when she is not receiving such treatment.

91. Dr Danbury's evidence is that he can give no time frame as to how long she would survive on mechanical ventilation on an ICU, it could be for several months and the burdens of continued treatment needs to be considered. Due to the length of time she has been on ICU in his opinion she has become more susceptible to the risk of infection, which could be immediate and very painful, with the consequence that she would die without her family being with her.

92. In considering AH's wishes the Official Solicitor considers that AH would not wish to remain in her current predicament, with the consequent continued pain and distress for many months until she succumbs to her condition or experiences a sudden and unpredictable death. The family's hope for AH to get better is against the weight of all the medical evidence, whilst understandable it is unrealistic. With no prospect of any further recovery it is the Official Solicitor's view that AH would not consider her painful, distressing existence remaining on ICU being cared for by others for the

majority of the time and being unable to do a single task for herself to be worthwhile. I agree with this analysis. I consider this analysis of her wishes takes into account her religious views which whilst clearly important to her, as well as the wishes of her family, those are not the only considerations in the very difficult position she is now in with the clear medical evidence about her condition and prognosis.

93. Having considered the evidence as a whole and weighed the respective benefits and burdens of continuing treatment, including carefully weighing in the balance the strong presumption that it is in AH’s best interest to stay alive, which would accord with her religious beliefs and is something her family strongly wish to happen, I have reached the conclusion that the very real burdens in the particular circumstances AH is in, with the prospect of no change and more probably a continued deterioration which may last many months of treatment, with the risk of an infection and dying away from her family, outweigh those very considerable benefits. If she is going to die her wishes are more likely to be that she would wish to do so with her family present.

94. I am acutely aware this is not the outcome this family would want. They have had to endure this extended period of uncertainty, whilst decisions are made about the application. The family members who have been a party to these proceedings have each acted with admirable dignity, bearing in mind the consequences for each of them of the decision the court was being asked to make. I have no doubt AH as a daughter, sister, mother and grandmother would have been proud of what they have done, as she clearly has been about each of them during her life prior to December 2020. They could not have done more for her and I hope now will be able to come to terms with the decision the court has made, acknowledging how difficult that will be for each of them.

95. For the reasons set out above, I will grant the declaration sought.

96. During the hearing there was evidence about what steps would be taken, in the event the court did make the declaration sought. Whilst recognising how difficult this decision is going to be for the family and they will need some time to absorb it. I hope that sensitive discussions can take place regarding the practical arrangements, and so far as is possible, the wishes of the family can be accommodated.