

Neutral Citation Number: [2021] EWCA Civ 1768

Case No: CA-2021-000012

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE COURT OF PROTECTION
MR JUSTICE HAYDEN
[2021] EWCOP 51

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 25/11/2021

Before:
SIR ANDREW McFARLANE
(President of the Court of Protection)

LORD JUSTICE MOYLAN and SIR NICHOLAS PATTEN

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Re:- AH

Edward Devereux QC (acting pro bono) and Olivia Kirkbride (instructed by Dawson Cornwell Solicitors) for the Appellants

Katie Gollop QC (instructed by Kennedys Law LLP) for the First Respondent

Nageena Khalique QC (instructed by The Official Solicitor) for the Second Respondent

Hearing date: 2 November 2021

# **Approved Judgment**

Covid-19 Protocol: This judgment was handed down remotely by circulation to the parties' representatives by email, release to BAILII and publication on the Courts and Tribunals Judiciary website. The date and time for hand-down is deemed to be 10:30am 25<sup>th</sup> November 2021.

## **Lord Justice Moylan:**

- 1. This case concerns the medical treatment of a person who, as in the judgment below, I will call AH. Her children apply for permission to appeal and, if permission is granted, to appeal from the order made on 3 September 2021 by Hayden J sitting in the Court of Protection. He declared that it was not in AH's best interests for her to continue to receive ventilatory treatment after 31 October 2021. The declaration did not take immediate effect because the Judge decided that a period should be allowed to enable family members to travel to see AH. The Judge's order has been stayed pending this court's determination.
- 2. At the hearing before the Judge, the children were acting in person. They have been represented at this appeal by Mr Devereux QC, Ms Kirkbride and their instructing solicitors, Dawson Cornwell, all acting pro bono. The NHS Trust is represented, as below, by Miss Gollop QC. The Official Solicitor, acting as AH's litigation friend, is represented by Ms Khalique QC, who also appeared below.
- 3. Initially, the application for permission to appeal relied on four grounds of appeal. It was contended that the Judge had failed:
  - "(a) to give sufficient consideration to AH's earlier capacitous decision that she wished to receive "full escalation" of treatment;
  - (b) to appreciate the overwhelming importance to AH of her religious and cultural views and the impact of those views in relation to the withdrawal of medical treatment;
  - (c) to consider adequately AH's past and present wishes and feelings;
  - (d) properly to balance the interference with AH's human rights under the ECHR."
- 4. Then, shortly before the hearing in this court, the Appellants received a Note (prepared by a representative of the Official Solicitor) of the Judge's visit to hospital to see AH, which had taken place after the parties had made their respective final submissions and before the Judge gave judgment. This led to a fifth ground of appeal being advanced, namely that the Judge's visit was wrongly used by him as an "evidence gathering exercise to establish what AH's views were", which "likely influenced his overall conclusions", and that this rendered his decision procedurally unfair because the parties were not given the Note of the visit, nor given an opportunity to make submissions in respect of the visit, prior to the judgment.
- 5. Mr Devereux emphasised in his submissions that the family recognise the care and "strikingly evident humanity" with which the Judge conducted the hearing and the manner in which he "interacted with the family in a deeply compassionate way". He also acknowledged the Judge's considerable expertise in cases under the Mental Capacity Act 2005 ("the MCA 2005").

6. At the outset of the hearing before us, the application for permission to appeal was opposed by the Trust while the Official Solicitor was neutral. However, when Ms Khalique came to make her oral submissions, the Official Solicitor's position had changed and she supported the appeal.

## Background and Hayden J's Judgment

- 7. The background is set out in detail in the Judge's judgment which is published: [2021] EWCOP 51.
- 8. AH is aged 56. She has four children, called in the judgment A, M, S and K. She had some underlying health conditions but was working and, as set out in one of the statements, prior to December 2020 was "leading a happy and fulfilling life".
- 9. AH was admitted to hospital at the end of December 2020 and was diagnosed as suffering from Covid-19. She has been cared for in hospital since then.
- 10. The Judge heard evidence and submissions over the course of three days. He had a significant amount of written and oral evidence. He had statements from the doctors (a Consultant Neurologist, Dr B, and a Consultant Intensivist, Dr A) responsible for treating AH in hospital and from the senior nurse responsible for the delivery of AH's nursing care. He had a report from Professor Wade, a Consultant in Neurological Rehabilitation, who had provided an independent opinion at the request of the treating clinicians and an expert report, provided for the proceedings, by Dr Danbury, a Consultant Intensive Care Physician. He had statements from each of AH's children and from AH's sister. The Judge heard oral evidence from all the doctors, from the nurse and from AH's family.
- 11. As the Judge states, at [96], there is "no doubt that AH lacks capacity to take her own decisions in relation to medical treatment". The issue, therefore, that he had to determine was whether it was in AH's best interests for her to continue to receive life-sustaining treatment, namely ventilatory treatment. The unanimous medical opinion from the treating clinicians, Professor Wade and Dr Danbury (who described his opinion as "finely balanced") was that it was not in AH's best interests for her to continue to receive ventilation.
- 12. The Trust sought an order that such treatment was not in AH's best interests. As set out below, AH's family had differing views with some opposing the Trust and others, if not agreeing with, not actively opposing the Trust. In her closing submissions, the Official Solicitor described this as an "extremely challenging" case (original emphasis) and submitted, as set out in the judgment at [103], that AH "should continue to be ventilated outside the hospital".
- 13. Following the conclusion of the hearing, the Judge went to visit AH in hospital. This visit was the focus of the fifth ground of appeal, as referred to above, and I propose to deal with it in some detail.
- 14. From the outset of the hearing, it is plain from the transcript that the Judge was considering going to see AH in hospital. There were a number of occasions during the hearing at which it was suggested, including on behalf of the family, that the Judge should go to the hospital. However, it is also clear that at no stage was there

- any discussion about the purposes of any proposed visit or how, procedurally, it would fit within or affect the hearing.
- 15. At the conclusion of the hearing, the Judge indicated that he would visit AH in hospital. This led to a very brief exchange with one of AH's children (A) as to whether, when the Judge visited, he would "ask her yourself". This was because, as A explained, he had gained the impression when he had been giving his oral evidence that the Judge "felt when I asked, she was saying to please me". This was a reference back to an exchange which had occurred during the course of A's oral evidence.
- 16. It appears from the transcript that A gave evidence of his belief that his mother had shaken her head when he had asked whether she wanted to end her life. The Judge had suggested to A that the response AH gave would or might depend on how the question was phrased. The Judge commented that the answer might be different if she was asked "are you tired, do you want some peace".
- 17. A few days after the end of the hearing, the Judge went to see AH in hospital. He spent some time with AH with only a nurse and a representative of the Official Solicitor present. As referred to above, a careful Note was taken by the latter. The Judge spoke to AH, who appeared to be distressed and was crying. The Judge said that he did not know what AH wanted and that "it's very, very hard for you to tell me". He then said, "I think it may be that you want some peace". Later, he said: "It is not easy for you to communicate, but I think I am getting the message".
- 18. The Judge then left the ward and saw two of AH's children. A asked the Judge whether he had asked her "the question". The Judge replied that he "got the clear impression she wanted some peace, she showed me that she did".
- 19. In his judgment, the Judge sets out his reasons for concluding that it was not in AH's best interests for her to continue to be on a ventilator.
- 20. The judgment describes, in detail, the manner in which AH's condition has developed since she was admitted to hospital. In summary, at [4], in January/February 2021 AH "developed a severe inflammatory response, a recognised complication of Covid-19, with hyperpyrexia (life threateningly high temperature) and other problems leading to multi-organ failure. She required renal dialysis, ventilation and sedation". The Judge later describes this episode, at [63], as a "cytokine/autoimmune 'storm" which has caused "devastating neurological" and other damage; "Dr B and Dr Danbury have seen similar 'storms' in other patients critically ill with Covid-19 although neither has seen damage as extensive as that sustained by AH".
- 21. The medical evidence was agreed that AH has sustained a number of profound neurological and myopathic conditions which are permanent, namely: (a) cerebral encephalopathy; (b) brainstem encephalopathy; (c) motor neuronopathy; and (d) necrotising myopathy. In non-medical language, AH has sustained, at [63], "extensive damage" to her nerves, muscles and brain. As set out in the judgment, at [64], "the muscle loss is 'massive'" and there was no prospect of "recovery of the muscle".
- 22. The Judge explains, at [6], that these conditions are "recognised and understood":

"The development and impact of the virus on AH may have followed an unfamiliar pattern and the resultant brain damage may be more extensive than commonly seen, but the nature and extent of the damage itself is both recognised and understood in contemporary neurological medicine. In this respect we are in known rather than unknown territory. Thus, how the Covid-19 virus came to cause this extensive damage may not yet be fully understood, but the consequence of the damage and likely prognosis is."

23. As set out in the judgment, at [69], AH is cared for in a critical care unit and is dependent on mechanical ventilation; continuous nursing care, which includes moving her frequently to seek to prevent pressure sores, as she cannot move herself apart from small movements of her head and neck; nutrition and hydration delivered via a nasogastric tube; and numerous medications. She requires frequent suctioning. The Judge described, at [50], the medical care that AH has received in these terms:

"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."

The Judge was equally impressed with the quality of the nursing care received by AH.

24. By May 2021, at [5], AH's condition was such that "concerns were raised [by the treating team] about continuing with active medical treatment and discussion about her best interests has continued since that time". As the Judge explains later in his judgment, at [46], Dr A sent an email to his colleagues on 6 May 2021 "succinctly signalling his concern":

"His email read as follows:

"concerns expressed within the NCCU consultant group about whether we are acting in her best interests. I share these concerns."

What I identify here, both from the email and from what Dr A said in evidence, is that there was a dawning realisation amongst the treating team that with AH's slight but significant improvement in awareness came a visible and marked increase in her distress. This, as Dr A told me, is also distressing to those treating her. It provoked a timely, patient centred response to consideration of the burdens and benefits of treatment and a critical evaluation of where AH's best interests lie. This approach is a meticulous application of the Guidance issued by the Royal College of Physicians and the BMA."

25. In July 2021, at [59], Dr B noted that AH "is suffering and distressed". The Judge records, at [60], that this is "a conclusion shared by the entire medical and nursing team and by the family", adding:

"The visible distress is undoubtedly punctured by occasional shafts of happiness, such as when AH sees her family. However, even when the family are present, distress is frequently exhibited. I strongly sensed that it is this that is causing the treating team such ethical concern as to where AH's best interests lie."

- 26. The daily consequences for AH of her conditions and the treatment she is receiving are severe. Her ability to move is minimal: she is, at [69(ii)], "unable to move other than small movements of her head and neck". She is, at [61], only "able to communicate with eyes, some neck and lip movement". The Judge describes, at [55], that AH "has no way of instigating communication or identifying her own discomfort or general needs". She is, at [72], "able to feel and show some degree of emotion" but "Predominantly, she now reveals pain and real distress".
- 27. Ventilation is, at [65], "highly burdensome" and the frequent suctioning required is, at [69(ii)], "extremely painful" (Judge's emphasis). She has to be turned frequently "to avoid pressure lesions" with the consequence that "her rest is constantly disturbed". The Judge records, at [70], that "it is a powerful tribute to the quality of nursing care that AH has managed to avoid bed sores. Sadly, this cannot be averted indefinitely, and they will significantly diminish her already seriously depleted quality of life".
- 28. At [69(iii)], the Judge states that: "The care for a patient in this condition is, in Dr A's words "associated with a total loss of dignity and a total loss of autonomy she is unable to provide consent and cannot participate in any meaningful choice about how she is treated".
- 29. Other "key facts" to which the Judge refers, at [69], are:
  - "(v) Until recently the treating team were concerned that if her consciousness level improved, she may become increasingly aware of her condition and its consequences and that her distress would worsen. They wished, if possible, to reach a consensus about her best interests before this occurred. They were concerned that whilst she may never recover capacity, the countervailing disadvantage of neurological improvement might be that her increasing awareness would be associated with inconsolable distress. It is Dr A's settled view that such a point has now been reached. Ms C (senior nurse) also agrees with this as does Dr B. Indeed, in my judgement there is universal professional consensus on this important point;
  - (vi) During examinations, and for some time now, AH has become distressed, cried and appeared anguished. This occurs on every occasion. As I have already mentioned, this is reported to be very distressing to those who are treating her, particularly the

nurses, because it makes them feel as if they are causing rather than alleviating discomfort;

- (vii) The above describes a parlous existence but into this misery are the shafts of sunlight created by the presence and reassurance of her family. This is plainly both meaningful and important to AH, but it does not abate her physical and mental discomfort which continues in their presence. This I also saw on my visit as well as M and A's sensitive efforts to ameliorate it. (I was shown a video of AH having a visit from her grandchildren. Her bed had been pushed out into the garden. She was undoubtedly happy to see them. I am also constrained to record that both the eldest son K and Ms C told me that AH had been initially resistant to the visit because they both strongly sensed she did not want her grandchildren to see or remember her in her present state);
- (viii) Dr A is "now deeply worried that her awareness has reached a point where all she is able to focus on is fear, anxiety, and hopelessness". He considers AH's "recall is minimal" ...;
- (ix) Dr A concludes that "I cannot reasonably believe that she would choose to live in this way, unless there was a clear signal from prior discussions with her family, or evidence of any previous statements she may have made or written"."
- 30. The medical evidence is clear that AH's treatment "will not reverse the neurological or myopathic injury" she has sustained. Professor Wade's opinion as to the prognosis for AH was as follows:

"It is my opinion that, beyond all reasonable doubt, the prognosis for significant further improvement is non-existent. There may be slight improvement over a further six months. For example, if zero was unconscious, and 100 was normal, and if we assume that her current level is perhaps three, she might move to four or even five. To live outside a residential placement, she would need to reach at least 15 on this completely arbitrary scale."

The Judge sets out the effect of the medical evidence, at [69(iv)]:

"It is impossible to reverse, treat, or ameliorate any of the effects of the damage to her peripheral nervous system or brain".

- 31. AH's life expectancy is, at [71], "significantly diminished ... certainly less than 12 months ... perhaps somewhere around six or possibly nine months".
- 32. The Judge's stark conclusions are, at [71], that:

"There is no guarantee that her death might not come unexpectedly, in consequence of untreatable infection (e.g. respiratory tract infection or infected pressure sore). AH is

dying. The ventilatory support here is not keeping AH alive, in order to equip her to respond to an underlying illness (for which it is designed), it is simply keeping her breathing. In a very real sense, it is not prolonging her life, it is protracting her death. Moreover, it is extending her pain at a time when her ability to feel it has increased and, sadly, whilst her enjoyment of life has remained tightly circumscribed."

## And, at [76]:

"AH's treatment is futile; she is dying slowly in both physical and emotional pain; her treatment is burdensome and exhausting; her rest is of necessity frequently interrupted and she is on a small noisy mixed-gender ward which affords her minimal privacy and fails satisfactorily to respect her cultural norms (this is unavoidable at present), her dignity is preserved by the tireless efforts of her doctors, the rigorously attentive care of the nurses, the sensitive and intimate care given by her daughter M, which is focused not only on her mother's comfort but on her presentation to the world and more generally, the love of her children and family, which is fiercely strong and entirely unconditional. AH's dignity, however, hangs by a thread. The challenge for all the professionals in this case, the family and the Court is as to how it can best be protected in these last months of her life."

- 33. The Judge addresses, at [72], the positive "comfort" AH "plainly sustains ... from the presence of her children who have been the focus of her life". This was because, at [74], she "retains the capacity to feel and receive love". Her children gave evidence that, at [72], AH is "able to derive peace from prayers from the Koran and has demonstrated some enjoyment of films shown to her on her iPad. Both M and A consider that she has a level of awareness of and interest in her favourite soap opera which they regularly watch with her. This is doubted but not actively contested by the medical team".
- 34. The Judge deals with AH's "likely wishes and feelings", from [79]. He sets out his assessment of each of the children because, he explains at [86], this provided some context for him "to evaluate their particular perspective on what their mother would want in her present circumstances". The Judge then deals with aspects of their evidence and the evidence from AH's sister in the next paragraphs.
- 35. The Judge refers, at [93], to his having identified "AH's religious and cultural views as [being] integral to her character and personality". However, he makes clear that he was not prepared to make any assumption "that AH would have taken a particular theological position on her treatment plan solely because she is a Muslim, even an observant one". He considers that this "risks subverting rather than protecting AH's autonomy", noting that "there is a range of opinion, within this Muslim family, as to what is the right course to take".

- 36. At [95], the Judge deals with the relevance of the content of a ReSPECT form from December 2020 and the submission made in respect of it on behalf of the Official Solicitor. I deal with this below.
- 37. The Judge next sets out the "framework of the applicable law". No criticism is made of his summary which includes reference to the MCA 2005 Code of Practice and to *Aintree University Hospitals NHS Trust v James* [2014] AC 591. The Judge quotes paragraph 5.31 of the former which states:

"All reasonable steps which are in the person's best interests should be taken to prolong their life."

He refers to the strong presumption in favour of prolonging life where possible. He quotes from Baroness Hale in *Aintree*:

- "22. Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."
- 38. The Judge's conclusions are set out at [102]-[108]. He rejects, at [103], the case advanced by Ms Khalique, namely that AH should be ventilated outside the hospital. This was because he accepted the medical evidence that "Continued ventilation outside the ICU is decidedly not a safe option".
- 39. Rather than summarise the rest of the Judge's analysis, I set it out in full:
  - "104. The medical and ethical challenges simply require to be confronted. AH retains the capacity to love and to be loved. She has moments of pleasure in the scorched landscape of her present existence. These are entirely related to the presence of her children. She is a woman who has most enjoyed peace, privacy, family life and prayer. Her present circumstances afford her little opportunity for any of these. As the medical evidence I have analysed above reveals, there is no prospect for any recovery, only a chance that she might experience further pain both physically and emotionally.
  - 105. At the parties' request I visited AH in hospital. I have already made reference to it in some of the passages above. I have paid tribute to the hospital staff and to the family, but I recognise that they both consider AH's present circumstances to fall short of meeting needs which she is entitled to expect to be addressed. At the end of her life, AH requires that which has most sustained her throughout, I reiterate this is peace, privacy

and the presence of her family. She also requires all that can be done to diminish her pain. This I consider is most likely to preserve her dignity as a human being onwards to the end of her life.

106. Mention has been made of a hospice in the locality. I am told that it is light, airy, newly built and very informal. There are no windows near AH in the ICU. M has repeatedly mentioned this fact and is plainly distressed by it, on her mother's behalf. I canvased with Dr A whether it would be possible to try to keep AH ventilated for a few weeks, outside the unit, to enable her to spend time with her family in privacy and in circumstances which would be of qualitative value to her. Dr A cautioned me of the danger of putting the family before the patient in this proposal. It involves a delay for AH until her daughter from overseas can be present. It will involve some continuation of burdensome and ultimately futile treatment. I have no doubt that Dr A was entirely right to sound a cautious note. My response to it, however, is that I believe the preponderant evidence establishes that it is what AH would want. Dr A was inclined to agree. None of the options in this case is free from risk or without ethical challenge. Ultimately, they have to be confronted as best we can, it is impossible to avoid them.

107. Miss Khalique has told me that the Official solicitor regards it as an understatement to describe the decision in this case as "extremely challenging". The Official Solicitor identifies it as "the most troubling and tragic of cases of this kind" with which she has been involved. The evidence, not least that given by the family, has identified a tentative plan which has crystallised, at least to some degree, during the course of the hearing. As I have analysed, it is centred upon respecting AH's dignity and promoting the best quality of life at this last stage. For it to be most effective it will require cooperation between the family and those caring for AH. This will require respect, each for the other. The time has come to give AH the peace that I consider she both wants and is entitled to.

108. In order that my decision is free from any ambiguity, I wish to set it out in simple terms: I do not consider that AH's best interests are presently met by ventilatory treatment in the ICU; ventilation is now both burdensome and medically futile; it is protracting avoidable physical and emotional pain. It is not in AH's best interests that ventilation be continued indefinitely. It is however in her interests that ventilation remains in place until such point as all her four children and family members can be with her. This, I am satisfied, is what she would want and be prepared to endure further pain to achieve. I am also clear that it is in her best interests to be moved to a place which protects her privacy and affords her greater rest. The details of these

arrangements can be worked out between the family and the treating team. One of the children is presently outside the United Kingdom and will have to make arrangements to travel. I hope this is possible, but I make it clear that ventilation should be discontinued by the end of October 2021. Though there is an inevitable artificiality to this, it reflects the delicate balance that has been identified. It provides an important opportunity for this close and loving family to be together at the end. The treating clinicians feel able to work with and perfect this plan and recognise that it is consistent with their own professional conclusions and reflective of the central importance of family in AH's hierarchy of values and beliefs."

40. The Judge, accordingly, made the order referred to above.

#### Determination

- 41. I would first emphasise that the "starting point", as explained by Baroness Hale in Aintree at [35], is "a strong presumption that it is in a person's best interests to stay alive". She also explained that, "this is not an absolute [because] [t]here are cases where it will not be in a patient's best interests to receive life-sustaining treatment". The Judge decided that it was not in AH's best interests for her to continue to receive life-sustaining treatment and the issue raised by the appeal is whether the Judge's decision was procedurally and/or substantively flawed such that his decision should be set aside and the application reheard. I propose to answer this by considering each of the grounds of appeal in turn, although I recognise that there is a degree of overlap in respect of the first three.
- 42. (a) The first ground, to repeat, is that the Judge gave insufficient consideration to AH's earlier capacitous decision that she wished to receive "full escalation" of treatment.
- 43. This is a reference to the "ReSPECT form", completed in December 2020. The acronym stands for: Recommended Summary Plan for Emergency Care and Treatment. It is a computer form which is completed by a clinician who has had, what is called, "a ReSPECT discussion" with a patient. The discussion is intended to ascertain the patient's views as to their priorities in the event of treatment being required in an emergency, if they are unable to make or express a choice. I would note, in passing, that it is not, as set out in the judgment and some of the written submissions, a form which is "completed" by AH.
- 44. The form, at that time, had a sliding scale between, at one end, "Prioritise sustaining life, even at the expense of comfort" and, at the other, "Prioritising comfort, even at the expense of sustaining life". The evidence was that AH indicated that she wanted, what was described in the evidence as, "full escalation of treatment". This led to the following submission made to the Judge, at [95], on behalf of the Official Solicitor:

"The Official Solicitor interprets this capacitous decision (made at a time when [AH] knew she was infected with Covid-19, and was unwell and that there was the possibility of medical intervention) as a strong indicator that [AH] wanted all steps to be taken to preserve her life."

The Judge rejected this submission:

"With respect to Miss Khalique, I do not think this note can support the weight she places upon it. As has been said, in evidence, AH would have been contemplating ventilatory support at the time the document was created. It is plain that she agreed to this and is likely to have recognised the highly significant level of medical intervention but, I am unable to extrapolate from this that she would have wished to remain connected to a ventilator in her present circumstances. Treatment in this case has been "fully escalated": there is no further treatment capable of being effective other than that which is directed to lessen her pain."

- 45. Mr Devereux effectively repeated the submission made by the Official Solicitor to the Judge as summarised above. He also relied on section 4(6)(a) of the MCA 2005 which requires a court to consider "the person's past and present wishes and feelings (and, in particular, any relevant statement made by him when he had capacity").
- 46. I agree with the Judge that the ReSPECT form does not bear the weight which Mr Devereux seeks to ascribe to it. It is directed, as is clear from the title, to *emergency* care and treatment. It is not directed to long-term treatment and so provides very little assistance to whether AH would want treatment to continue in her current condition which is very far from an emergency.
- 47. (b) The second ground is that the Judge failed to appreciate the overwhelming importance to AH of her religious and cultural views and the impact of those views in relation to the withdrawal of medical treatment. This is closely connected to the third ground because, in effect, it is a submission that the Judge's conclusion as to AH's wishes and feelings, or as he describes it, at [106], what she "would want", is flawed because he failed to give sufficient weight to AH's religious and cultural views when determining her wishes and feelings.
- 48. In my view, this is not a sustainable ground of appeal. The Judge was aware of, and took into account at [93], that "AH's religious and cultural views are integral to her character and personality". This was consistent with the submissions made by Ms Khalique that religion "was a central part of [AH's] life". The Judge clearly considered *all* the evidence and was entitled to conclude, at [93]:
  - "... I am not prepared to infer that it would follow that those views would cause her to oppose withdrawal of ventilation in these circumstances ..."

I would add that the weight to be given to a particular factor is for the trial judge and not for this court.

49. (c) The third ground is that the Judge failed adequately to consider AH's past and present wishes and feelings.

- 50. Mr Devereux submitted that the Judge's conclusion as to AH's wishes and feelings is "disconnected from the evidence", in part because he "ignored" the evidence from the children as to what AH would want. I would agree that the Judge does not address the evidence from AH's children on this issue in as much detail as he might have done. However, I do not accept that the Judge "ignored" their evidence. The Judge deals with their evidence and notes, at [93], that there was "a range of opinion" within the family as to what should happen; at [68], that "there is at the very least one family member who unambiguously supports the professional consensus and others within the family who reflect varying shades of sympathy and agreement to the medical analysis"; and, at [67], to there being "differing views within the family" as to the withdrawal of ventilation.
- 51. It is also clear from aspects of the evidence that, at least, some members of AH's family do not accept that AH has a limited life expectancy. During the course of the oral evidence one of the children said that AH "would want to get better". It is clear from the medical evidence that there is no prospect of AH getting "better" to any significant extent.
- 52. In my view it is clear, first, that the Judge did consider AH's wishes and feelings. The contrary is not arguable because the Judge expressly considered, from [79], AH's "likely wishes and feelings in respect of the medical options in her present circumstances". Further, the Judge returned to this issue when considering whether the continuation of ventilation was or was not in AH's best interests.
- 53. Secondly, I am not persuaded that the Judge did not "adequately" consider AH's wishes and feelings. As referred to above, the Judge considered these between [79]-[95] and again when setting out his conclusions. What is in reality challenged is his conclusion that AH would not want ventilatory treatment to continue and, subject to ground 5, this was, in my view, a decision which the Judge was entitled to reach.
- 54. (d) The fourth ground is that the Judge failed properly to balance the interference with AH's human rights under the ECHR.
- 55. This ground adds nothing to the other grounds of appeal. The balance to be applied in this case is clear and is the balance applied by the Judge. It is whether to continue to provide ventilatory treatment is or is not in AH's best interests.
- 56. (e) The fifth ground of appeal relates to the Judge's visit to see AH in hospital.
- 57. Mr Devereux submits that this visit, and what the Judge appeared to take from it, was flawed and wholly undermined the fairness of the process and the validity of his decision.
- 58. Mr Devereux submits that the visit was flawed because no consideration was given to its purpose. He referred us to the Guidance, "Facilitating participation of 'P' and vulnerable persons in Court of Protection proceedings", issued on 3 November 2016 by Charles J, as Vice-President of the Court of Protection. This is, currently, the only published Guidance on what should happen when a judge sees P.

"Meeting with the Judge

- 14. If P wishes to meet with the Judge, it must first be determined what the purpose of such a meeting would serve and the court and the parties must be clear about that in the particular case. In addition, consideration should be given to:
- (a) Informing the Judge/regional hub of P's wish, and seeking the Judge's views as soon as possible, providing the Judge and court staff with any relevant information about how such a meeting might take place to maximise P's participation, and seeking their views about what is practicably possible, taking into account the above suggestions;
- (b) Alerting the Judge and court staff to any risk issues which may be relevant for a visit by P to see the Judge at the Courtroom or in the Court building, or for the Judge visiting P at a care home or hospital;
- (c) Who else might attend such a meeting?
- (d) Whether the meeting should be video or audio recorded and if so how and by whom?
- (e) Whether a note is to be taken of the meeting and if so by whom?"

It can be seen that, in the present case, it was not determined what purpose would be served by the Judge visiting AH in the hospital. Also, the guidance is about P wishing to meet the judge rather than addressing the situation which developed in the present case, with the Judge ultimately simply informing the parties that he would visit AH in hospital.

- 59. Mr Devereux also pointed to the clear guidance given when a judge meets a child who is the subject of proceedings in "Guidelines for Judges Meeting Children who are subject to Family Proceedings", published in April 2010 by the Family Justice Council and approved by the then President of the Family Division. This provides:
  - "6. If the meeting takes place prior to the conclusion of the proceedings –

. . .

(iv) The parties or their representatives shall have the opportunity to respond to the content of the meeting, whether by way of oral evidence or submissions."

He submits, again acknowledging the Judge's very great experience, that the Judge's visit to the hospital fell on, what was described in *Re KP (Abduction: Child's Objections)* [2014] 2 FLR 660, at [56], as "the wrong side of the line".

60. Mr Devereux's first substantive submission is that the Judge took into account what occurred when he visited the hospital when making his decision. He used it as "an evidence gathering exercise to establish what AH's views were and the visit likely

influenced his overall conclusion". Mr Devereux submits that this is a reasonable inference from the Judge saying to AH, "I think maybe you want some peace" and "It is not easy for you to communicate, but I think I am getting the message"; and saying to the children at the hospital that he "got the clear impression she wanted some peace, she showed me that she did". He submits that this resonates with the Judge's use of the word "peace" during the hearing (as referred to in paragraph 16 above) and his conclusion in the judgment, at [107], that, "The time has come to give AH the peace which I consider she ... wants".

- 61. This was, he submits, procedurally unfair because AH's children did not have an opportunity to make submissions on the Judge's assessment of his visit. Mr Devereux acknowledges that the effect of the visit is partly speculative but submits that this is because the purpose of the visit was not determined in advance and because the Judge did not subsequently tell the parties whether, and if so how, it informed his decision.
- 62. Secondly, Mr Devereux submits that the Judge was not equipped to draw from his visit any conclusions or insights as to what AH might want. The medical evidence shows that AH is in a "Minimally Conscious State-plus"; is unable to communicate; and has only a very limited ability to move, meaning that it is not easy to evaluate any response she might give. Dr Danbury, for example, concluded that he was not able to establish AH's wishes.
- 63. Miss Gollop acknowledges that it would have been better had the Note of the Judge's visit been circulated to the parties prior to his giving judgment. However, she submits that, if this was a procedural irregularity, it was not one which affected the outcome of the case because there was nothing that happened at the visit that changed the Judge's determination of AH's best interests.
- 64. She submits that it is inherently unlikely that the Judge used the visit for the purposes of gathering more evidence after the effective conclusion of the hearing. Miss Gollop also submits that it is highly unlikely that any relevant new evidence came to light in part because, if it had, the Judge would have informed the parties of that and invited further submissions. Her reading of the Note is not that the Judge was getting a direct sign or indication but that he was "alluding to the picture painted by the totality of what he knew". She acknowledges that it is possible that the visit influenced the Judge's decision but not in any way material to this appeal. It provided the Judge with the opportunity to see for himself what the witnesses had described, namely a ventilated and near totally paralysed patient, in a busy, noisy intensive care environment, who was distressed and crying.
- 65. In summary, Miss Gollop submits that the Judge did not use the visit for the purposes of gaining any information about, or insight into, AH's wishes and feelings and that it did not change the Judge's mind but confirmed the decision he had already made. She also submits that we cannot conclude that, absent the Judge's visit, he would have come to a different conclusion nor that it was pivotal to his decision. In her submission, it is, therefore, not a procedural irregularity which renders the decision unjust or which requires the application to be reheard.
- 66. Ms Khalique submits, in respect of ground 5, that the purpose of the Judge's visit to the hospital was "not information gathering". In her submission, the Judge had

- already come to his own conclusion about ventilation and the visit was not to elicit AH's wishes and feelings or to gain any further insight to inform his decision.
- 67. She accepts, however, that the Judge's visit was open to different interpretations. She accordingly submits that there ought to be clearer guidance including, in particular, about the need to consider in advance of a Judge seeing or meeting P what the purpose is and how any visit fits within the hearing of an application.
- 68. This is not an easy case. It has been described, as referred to above, by the Official Solicitor as extremely challenging and by Dr Danbury as finely balanced. It is not clear that the Judge agreed with these descriptions, but they provide some indication of the context for our decision on this appeal.
- 69. I have, very regrettably, come to the conclusion that the Judge's decision cannot stand and must be set aside. I say, very regrettably, because he clearly gave this case a great deal of careful consideration, as is accepted by all parties, and the description of AH's current situation and prognosis is, indeed, bleak. But, in a case which concerns the continuation of life-sustaining treatment it is particularly important that the process leading to the decision is not procedurally flawed.
- 70. I agree that what happened when the Judge saw AH in hospital is capable of more than one interpretation. However, in my view, it is clearly capable of being interpreted as submitted by Mr Devereux. The language used by the Judge is capable of indicating that he did consider that AH had given him some insight into her wishes. The words, "I got the clear impression she wanted some peace, she showed me that she did" are capable of that interpretation.
- 71. If that is right, the Judge's decision is undermined for two reasons. First, it is strongly arguable that the Judge was not equipped properly to gain any insight into AH's wishes and feelings from his visit. Her complex medical situation meant that he was not qualified to make any such assessment. If the visit was used by the Judge for this purpose, the validity of that assessment might well require further evidence or, at least, further submissions.
- 72. Secondly, in order to ensure procedural fairness, the parties needed to be informed about this and given an opportunity to make submissions.
- 73. As referred to above, Miss Gollop submits that any procedural unfairness did not impact on the Judge's decision and does not make his decision unjust. The problem I have with that submission, apart from the importance of fairness, is that, although she *may* be right, I am not persuaded that she is necessarily right. I consider it certainly possible that it *might* have had an effect on the Judge's ultimate determination. Certainly, it would have had an impact on the Judge's assessment of a key factor, namely AH's wishes and feelings and, therefore, might have had an impact on his ultimate determination.
- 74. I do not, therefore, consider that the Judge's decision can be upheld. Accordingly, I propose that permission to appeal is granted and the appeal allowed. There will need to be a rehearing which will have to take place as soon as possible.

- 75. Finally, we were told at the hearing that some judges hearing cases involving life-sustaining treatment will often, if not frequently, visit P. Having regard to what has happened in the present case, it seems clear, as suggested by the Official Solicitor, that further consideration needs to be given as to what guidance should be given, additional to or in place of that set out in the Guidance issued by Charles J. However, until that takes place, it is clear that the following matters should be addressed and, if possible, addressed in advance of the final hearing so that any visit can be included as appropriate within the court process. Clearly, these matters will need to be determined before any visit takes place and after hearing submissions or observations from the parties:
  - (a) Whether the judge will visit P;
  - (b) The purpose of any visit;
  - (c) When the visit is to take place and the structure of the visit (in other words, how the visit it to be managed; what is to happen during it; and whether it is to be recorded and/or a note taken);
  - (d) What is to happen after the visit. This will include, depending on the purpose of the visit, how the parties are to be informed what occurred; when and how this is to happen; and how this will fit within the hearing so as to enable it to be addressed as part of the parties' respective cases.

#### Sir Nicholas Patten:

76. I agree with both judgments.

## Sir Andrew McFarlane, President of the Court of Protection:

- 77. I also agree that the appeal must be allowed for the reasons that my Lord, Lord Justice Moylan, has given.
- 78. This appeal has demonstrated that it is now the practice of some, and it may be many, judges in the Court of Protection ['CoP'] to visit the subject of the proceedings, P, when it is not possible for P otherwise to join in the proceedings. Such a practice may well be of value in an appropriate case. It is, however, important that at all stages and in every case there is clarity over the purpose of the encounter and focus on the fact that at all times the judge is acting in a judicial role in ongoing court proceedings which have yet to be concluded.
- 79. In the present case there was, regrettably, a lack of clarity over the purpose of the visit and the role of the Judge in undertaking it. If, as my Lords and I have accepted, it may have been the case that Hayden J was seeking to obtain some indication of AH's wishes and feelings, then great care was needed both in the conduct of the judicial interview and the manner in which it was reported back to the parties so that a fair, open and informed process of evaluation could then be undertaken within the proceedings.

80. More generally, the light shone by this case on the apparently developing practice of judicial visits to P indicates that there is a pressing need for the CoP to develop some workable guidance for practitioners and judges in a manner similar to that which is available in the Family Court with regard to judges meeting with children who are subject to contested proceedings. Whilst the circumstances in a children case, and the reasons for any judicial encounter, may differ from those that apply in the CoP, the need for clarity of purpose and procedural fairness are likely to be the same. In recent times, the CoP has established a multi-disciplinary forum known as 'The Hive in which matters of professional and jurisdictional importance are debated and developed. I propose to invite 'The Hive' urgently to consider the issue of judicial meetings with P so that a Practice Direction or Presidential Guidance on the topic may be issued. Pending such direction or guidance, I would endorse the approach described by Moylan LJ at paragraph 75 of his judgment.