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Case No: 13783897

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 03/09/2021

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

- -

Between :

Cambridge University Hospitals NHS Foundation Trust	**Applicant**
- and -	
AH	**1st Respondent**
(by her litigation friend the Official Solicitor)	
- and -	
A	**2nd Respondent**
(acting in person)	
- and -	
M	**3rd Respondent**
(acting in person)	
- and -	
S	**4th Respondent**
(acting in person)	
- and -	
K	**5th Respondent**
(acting in person)	

- -
- -

Ms Katie Gollop QC (instructed by **Kennedys Law**) for the **Applicant**
Miss Nageena Khalique QC (instructed by the **Official Solicitor**) for the **Respondent**
A,M,S & K (acting in person)

Hearing dates: 17, 18, 19th August 2021

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered following a remote hearing conducted on a video conferencing platform and was attended by members of the public and the press. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the respondent 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.

The Honourable Mr Justice Hayden :

1. I am concerned, in this application, with AH. She is 56 years of age. She has been an inpatient at Addenbrooke's Hospital, Cambridge, since the end of December 2020, where she was admitted, on an emergency basis, suffering with severe symptoms of Covid-19. The impact of this insidious virus upon AH has been brutal. I have been told, authoritatively, that in terms of the neurological impact and complications AH is *"the most complex Covid patient in the world"*. This conclusion was arrived at following consideration of both national and international case studies.

2. On any view, the evidence in this case is extremely challenging. None of the available options is devoid of difficulty. The impact of this virus on AH has created an invidious dilemma both for her family and for the professionals caring for her.

3. The central issue is whether AH's ventilatory support should continue. There is agreement between all the parties that AH lacks the capacity to give or withhold consent for medical treatment. AH's family members have exhibited a wide spectrum of views whilst endeavouring to advance a collective and unified response. In truth, each family member has, both knowingly and otherwise, vacillated as to the best way forward. This, I consider, is because there is no solution which is in any way comforting. Equally, it is imperative that a decision be taken as to where AH's best interests lie. The family recognise this.

4. On 18th December 2020, AH experienced her first symptoms of Covid-19, and was admitted to hospital on the 29th December 2020, when she presented with diarrhoea. Over the next 36 to 48 hours she deteriorated and was admitted to the critical care unit. After two or three days there was some improvement but, on 9th January 2021, she 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.

5. On 13th January 2021, she was noted to respond to commands. She was then observed to be developing other symptoms and was diagnosed as having a critical illness neuropathy and myositis (weak and aching muscles). AH's condition continued to deteriorate, and she developed symptoms and signs indicative of brainstem and basal ganglia dysfunction. An MRI scan, taken on 20th January 2021, confirmed widespread abnormal changes throughout the brain. There was yet further neurological deterioration. Towards the end of January, she started to recover a little, showing some responsiveness. In mid-February AH had a nerve and muscle biopsy which showed evidence of necrotising myopathy and severe loss of peripheral motor nerves. Her clinical situation stabilised, with some detectable improvement, in March. In May concerns were raised about continuing with active medical treatment and discussion about her best interests has continued since that time. The treating clinicians solicited an independent opinion from Professor Derick Wade, a consultant in neurological rehabilitation. Professor Wade was asked to give a formal opinion upon AH's current state, prognosis and management options. The instructions were predicated on 3 premises:

i. the treating team think that it would not be in her best interests to continue active medical treatment;
ii. the clinical situation is very unusual; and
iii. there is disagreement from at least some family members.

6. Professor Wade has summarised the background medical history, with characteristic detail. All have agreed on its accuracy and I am therefore able to draw upon it in framing the background to this application. I propose to do so at some length, precisely because the clinical presentation is highly unusual and because any understanding of the issues presented by this case requires this background to be fully appreciated. I preface what follows by emphasising that AH is no longer infected by the Covid-19 virus, in respect of which a great deal remains unknown, despite the remarkable trajectory of medical knowledge within the last 18 months. What is in focus is the neurological impact of the virus on AH's brain. This territory is far more familiar to the treating clinicians and expert witnesses. 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. I set this out as clearly as I am able, because I know that some of the family members have struggled to absorb it, largely in consequence of their profound distress and evolving grief.

Medical Background

7. AH had been seen, in the past, in the rheumatology clinic showing signs of non-specific arthralgia, and had been discharged. She had elevated calcium levels. She had a previously recorded level of HbA1c of 53 (slightly raised) and suggestive of Type 2 diabetes. She had been diagnosed with carpal tunnel syndrome. She was taking vitamin D. She did not smoke, nor did she drink alcohol. She worked as a finance assistant at the University of Cambridge. I would add that she commenced this employment shortly before what has become known as the first national 'lockdown' and felt extremely proud to be working for the university.

8. On or about 15th December 2020, AH developed diarrhoea, which was unusual for her, and it worsened. She became worried about loss of fluid and electrolytes and attended the accident and emergency department at Addenbrooke's hospital on 27th December. Unfortunately, AH did not remain long enough to be seen.

9. AH presented again on 29th December. She reported a cough brought on by movement or when she went up and down the stairs, which made her feel short of breath. She had a sore throat and an intermittent raised temperature. She felt lethargic. When examined she appeared well, but she became short of breath when talking. She had tachycardia. The initial diagnosis was of Covid-19. An ultrasound of her upper abdomen revealed hepatic steatosis and gallstones. Two further doctors concurred with the assessment. The symptoms of Covid-19 were dated to 18th December. She was admitted to hospital.

10. On 30th December 2020 there was a remote pre-screening for possible involvement in a national Covid-19 trial. The diagnoses noted by the assessor included:

i. arthralgia;
ii. ulna impaction syndrome (wrist pain on the ulna side);
iii. carpal tunnel syndrome;
iv. Covid infection;
v. elevated serum calcium and elevated parathyroid hormone.

11. The trial assessment also recorded, on a checklist, that her radiographic severity score was greater than three; it was four, the highest level.

12. Clinically the CRP (C-Reactive Protein, a marker of an inflammatory response) was greater than 40. It was noted that she desaturated on mobilising to the toilet, with saturations dropping to 76%. On four litres of oxygen, through her nasal cannula, her oxygen saturation was 92%. A venturi mask was recommended.

13. Shortly afterwards it was reported that AH was not wearing her venturi mask as she felt claustrophobic. Her blood glucose, measured by BM stix, was 16.3 (raised). She was then reluctant to have dalteparin. After some explanation she agreed. She stated that she did not wish to be *"used as a guinea pig"*.

14. At 05:18 hours on 31st December 2020 she was "*in extremis*" with a saturation level of 72% and profound tachypnoea. She refused intubation but she was felt to lack the mental capacity to make that decision. It was noted in a ReSPECT discussion (a form recording a patient's wishes in the event of deterioration and loss of capacity), dated 29th December that she wanted full escalation of treatment. I have been told that this form is regularly updated, the advantage of which is obvious. However, as the form updates, it obliterates the earlier recording, the disadvantage of this is equally obvious and requires to be reassessed. This document, I am satisfied, reflects an immediate response to crisis situation.

15. On 31st December 2020, AH was admitted to the intensive care unit. She was at that time on dexamethasone, sedation and muscle paralysing medication. Her chest x-ray showed bilateral lower lobe and peripheral predominant multiple opacities. A little later she telephoned her son, A and daughter, M. They arrived on the ward, speedily somehow bypassing security. They reported that their mother had called fearing that she was about to be *"put to sleep"*. All agree that AH had, in the last few years of her life, in particular, frequently exhibited signs of anxiety.

16. On 2nd January 2021 at 18:34 hours she was diagnosed as having respiratory failure and suboptimal glycaemic control, and she was intubated with an endotracheal tube in place. She was paralysed. She was continued on fentanyl. On 3rd January 2021 at 09:33 hours she had a further episode of acute desaturation. There were some problems with absorption of her nasogastric tube feeding and she was becoming dehydrated. On 4th January 2021 treatment was started for her hypercalcaemia. Her muscle paralysing medication had been stopped on 3rd January 2021. Her food absorption was improving.

17. Later, on 4th January she was being considered for transfer out of intensive care. Shortly after midday her daughter, M, expressed concerns, and wanted her mother to be given a mobile phone which would recite the Koran to her. Later that day the process of ventilatory weaning was started. Overnight there was a slight increase in the amount of oxygen required. By 6th January she was off propofol but on fentanyl. She was weaned onto continuous positive airway pressure ventilation, and sedation was reduced. On 7th

January 2021 she was transferred out of the neurosciences critical care unit. She was on a sliding scale for her insulin. She was on cinacalet for hypercalcaemia. She remained intubated.

18. On 9th January 2021 she was noted to have continuing pyrexia, agitation and acute hypertension. Later, on the 9th, active ventilation was started again, and it was noted that overnight she had had severe hyperpyrexia which was attributed to Covid-19 Later that day she had the insertion of a central venous catheter. Attempts to insert a line into her left radial artery were unsuccessful. She was noted to have a severe inflammatory response without good evidence of new sepsis, and it was felt to be related to Covid-19. An arterial line was inserted successfully.

19. At 12.49 hours she had an echocardiogram which showed hyper-dynamic bi-ventricular function in keeping with vasoplegia. She was undergoing active cooling and by 15:48 hours her temperature had returned to 34.7. Later still on the 9th January, she was noted to have severe thrombocytopenia, which was related to acute disseminated intravascular coagulation.

20. On 10th January at 02:07 hours AH's temperature had reached 35.9C. By 07:13 hours she was much improved. A review at 07:19 hours noted that she was on three antibiotics and that her sedation had been changed. The severe instability over the previous 24 hours was noted: her temperature raised and then fell, she needed cardiac support, and she had external cooling in place. The differential diagnosis was between Covid-19 and bacterial sepsis. She had one unit of blood transfused. Later, on 10th January 2021 the diagnoses included:

    i. Covid-19 pneumonitis;

    ii. vasodilatory shock;

    iii. acute kidney injury on dialysis;

    iv. disseminated intravascular coagulation;

    v. possible stress cardiomyopathy;

    vi. diabetes mellitus and hyperparathyroidism.

21. A note on 11th January 2021 records that her daughter, M, said that her mother was a *"very panicky person"*. On 13th January 2021 it was noted that AH was developing anaemia. A pulse rate was stable at 110 bpm. Her renal dialysis had been stopped. On 13th January in the evening in a discussion with M, it was felt that she had improved from the weekend but that she might need a tracheostomy. Sedation was retained. On 13th January 2021 she was taken off sedation; she had raised blood pressure and was tolerating her endotracheal tube. It was recorded *"appears very weak – will meekly protrude tongue to command and has eyes open but does not squeeze hand with any vigour*." The diagnosis later that day was identified as "*Covid pneumonitis with multi-organ failure"*.

22. On 14th January it was noted that AH was not obeying commands. There was intermittent forehead twitching. Because this might have been due to epileptic seizures,

she had an electroencephalogram which revealed *"there is no evidence of status epilepticus, no electrographic seizures. Brief periods with a regular frequency eyebrow flutter were noted on two occasions, at the time of eye-opening following nail bed pressure. There is no EEG correlate".* One unit of blood was transfused later that day.

23. On 15th January AH had a CT brain scan. This was reported "*no focal brain lesion. No extra-axial collection. No hydrocephalus. There are involutional changes, a little more than would be expected for age.*" Later, on the same day, it was noted that she had abnormal liver function tests. She was on levetiracetam in case she had epilepsy. Twitches continued. On 16th January it was recorded that her eyes were open and that she was obeying some commands, but she was very weak. Twitching continued. It was in the eyebrows. On 17th January the family reported that, when on FaceTime, she tried to stick her tongue out.

24. Examination at 13:55 hours showed that she could look left and down to command, but not right or upwards with her eyes. Tongue protrusion was present. Arm reflexes were absent. The doctor wrote "*looks very much like critical illness myopathy. Facial movements are hard to explain in the oculomotor palsy should not be present with the usual myopathy. Facial movements are more reminiscent of tardive dyskinesia in some ways and of seizures or tics*.".

25. On 18th January 2021 she had a tracheostomy. In the evening, at 20.36 hours, she was examined by Dr B, a Professor of neurological genetics and Honorary Consultant Neurologist. He has led AH's care since 18th January 2021. It was very clear from his oral evidence that he knows his patient well and is alert to the reality of her daily circumstances. I suspect that the highly unusual evolution of her response to the virus has led him to take a very keen professional interest in her care. The examination revealed:

    i. the eyes opened to speech;
    ii. she intermittently obeyed commands;
    iii. there was no effort to speak (she had a tracheostomy);
    iv. pupillary reflexes and corneal reflexes were present;
    v. oculocephalic reflexes were present;
    vi. she had ocular bobbing – a slow drift upwards held for a time then a downwards saccade;
    vii. she had subtle skew deviation (right over left) and divergence (ocular imbalance);
    viii. the eyebrow tremor was variable, growing in amplitude while ocular bobbing was going up;
    ix. she had intermittent jaw tremor with no evident little tremor;
    x. the limbs were flaccid with marked quadriparesis;
    xi. there were no spontaneous movements or reaction to pain in any limb;
    xii. only knee jerks were present.

26. The neurologist, Dr B, felt that the diagnosis was brainstem encephalopathy combined with marked critical illness myopathy (or more likely mono-neuritis multiplex). He felt it was not epileptic and that anticonvulsants should be removed.

27. On 20th January 2021 AH underwent an MRI brain scan. The final report stated:

> *"the widespread bilateral asymmetrical areas of cortical abnormal signal on the FLAIR sequence which are subtle but more evident when narrow windows are used. These are present in both frontal lobes, the left parietal and occipital lobes, and also in the heads of both caudate nuclei and the cerebellum. No restricted diffusion is identified in these regions. There is also slightly increased T2 signal intensity in the bilateral superior cerebellar peduncles. Brainstem otherwise appears normal. These changes are non-specific but I think most in keeping with hypoxic/ischaemic injury; possible differential diagnoses include effects of seizure activity or extra pontine myelinolysis."*

28. The initial report records:

> *"there is no intracranial haemorrhage or collection. There is no evidence of acute or previous infarct and there are no micro haemorrhages. Normal vascular flow voids demonstrated. Normal ventricles and basal cisterns. There is generalised mild involution, the degree of which is slightly greater than expected for age."*

29. On 22nd January it was noted that she had ongoing tachycardia and hypertension. Treatment with bisoprolol was underway. Examination showed response to commands was absent. Her eyes were open. There was slight rhythmical protrusion and retraction of the tongue together with rhythmic eyebrow flickering. On 23rd January 2021 she was transferred back to the neurology critical care unit. Later she had a lumbar puncture performed. The opening pressure was 19 cm of water. The fluid was clear. On 24th January at 05:56 hours she was noted to be asleep with occasional eye-opening. She was not on sedation. Again, on 25th January, she showed no response to command, and no eye-opening. Later, on the 25th, she opened her eyes to pain, but did not show visual fixation or pursuit, and did not response to visual threat.

30. On 26th January she only opened her eyes to pain, and there was no motor response to noxious stimuli. There were no spontaneous breaths despite a long trial without ventilation. Corneal reflexes and cough reflexes were absent. She continued to show ocular bobbing, torsional nystagmus and skew deviation.

31. On 26th January 2021 AH underwent nerve conduction studies and electromyography studies. The results read:

> *"there are well preserved sural responses, although upper limb sensory responses are small/unobtainable. It is noted that she had bilateral median neuropathies when seen previously (6 November 2019), and there is currently some bilateral mild arm oedema. However, there does appear to be some attenuation of upper limb responses beyond that expected. Motor responses are either unobtainable or very small. EMG shows no spontaneous activity at rest, no motor units activated."*

32. A further attempt to withdraw ventilation on 26th January 2021 showed no respiratory effort even with significant rise in carbon dioxide. On 27th January 2021 AH was reviewed again by Dr B, he noted:

> "*eyes open to pain. Withdrawal to pain (could not get any response to commands). No attempt at speech. Takes some breaths if support reduced. Initially no eyebrow or jaw tremor. Towards end of assessment this developed. Her mouth movements seemed to coincide with attempted respirations – these were out of sync with ventilation and cause some desaturation. These movements had a rhythmic quality with a frequency of 1 to 2 Hz. There was no evidence of epilepsy. Pupils equal and reactive. Corneals reduced/absent. Ocular bobbing still evident and again increased as tremor developed. Roving lateral eye movements – oculocephalic reflexes seemed intact. Bilateral facial weakness. Lax jaw. Spontaneous tongue movements. Peripherally flaccid with no spontaneous movement. No response to pain and no tendon reflexes in any limb. Plantars mute."*

33. His impression was:

> *"essentially her neurological state seems to have deteriorated. The absence of lateralising features and global nature (peripheral and central nervous system) suggest a metabolic cause."*

34. Investigation showed a high ammonia level and treatment with lactulose and rifaximin was recommended. On 28th January 2021, she was still off sedation and she showed roving eye movements but no response to pain. A further review by Dr B suggested she was deteriorating further. The patient was reviewed by PD who was investigating any metabolic causes. He did not have any definite ideas but felt that the investigations planned or undertaken were appropriate. He did not think that the ammonia was relevant.

35. On 28th January 2021 AH had a further MRI brain scan. The report identified:

> *"subtle asymmetrical cortical FLAIR hyper intensity in the frontal lobes, the insula and the left parietal, occipital and temporal lobes is unchanged. There is persisting subtle FLAIR hyper intensity of the caudate nuclei, with new T2 and FLAIR hyper-intensity of the globi pallidi and substantia nigra. There is associated restricted diffusion of the globi pallidi and substantia nigra. Subtle T2 hyper intensity of the superior cerebellar peduncles has slightly improved. There is also a new small focus of white matter hyper intensity in the right centrum semiovale, with no associated restricted diffusion. A small T2 hyperintense focus in the left inferior white frontal matter is unchanged. There are no areas of haemorrhage. There is no associated mass effect, with no hydrocephalus effacement of the basal cisterns.*
>
> ***Conclusion**. In addition to the previously described findings, there is new T2 hyper intensity and restricted diffusion in the globi pallidiI and substantia nigra. Hypoxic-ischaemic injury remains the most likely cause, although other toxic/metabolic causes are possible."*

36. On 29th January 2021 there was a cardiac arrest call. AH apparently ceased respiratory efforts, and was unresponsive, and this may have been preceded by periods of relative increase and decrease in cardiac rate. The cardiac monitor showed asystole. The cause was uncertain, but it was not due to any problem with her serum potassium. A CT brain scan showed *"no intracranial haemorrhage, no large artery territory infarct. There is subtle hypo-attenuation of the globi pallidi bilaterally but the other abnormalities shown on the MRI of the day before are too subtle to be evident on the CT. No new diagnoses are identified. No midline shift, hydrocephalus or effacement of the basal cisterns."* She also had a CT pulmonary angiogram. The conclusion was *"no pulmonary embolus within limits of this study. Mild interval increase in the pulmonary artery calibre could represent pulmonary arterial hypertension. For cardiology review. Interval improvement in the bilateral ground glass opacities is in keeping with Covid pneumonitis. Increase in patchy consolidation. Mucoid impaction in the left lower lobe possibly related to aspiration."*

37. On 30th January 2021 she had abnormal nerve conduction studies reported as: "*not likely neuropathy: possible myopathy*". On 31st January she had an episode when she became hypertensive and tachypnoeic with a drop in her pulse rate to 52 bpm. This had occurred after suctioning. The IVIG (Intravenous immune globulin) started on 31st January 2021. The weaning process was started to reduce ventilation. On 1st February 2021 she started on L-dopa (rotigotine patch). AH had another electroencephalogram on account of movements in the eyes and face. The report read:

> "*the EEG, recorded in this poorly responsive patient, ventilated via tracheostomy, is abnormal. The patient had intermittent twitching of the jaw and lips, sometimes in synchrony with respiration, but sometimes independent jerks of the upper lip in particular. In addition, there are episodes of transient deviation of the eyes or jerky movements of her eyes at times (difficult to visualise well on video, but confirmed with Dr at the bedside). None of these episodes is associated with the change on the EEG.*
>
> *The ongoing activity is of low amplitude, but continuous and of mixed frequency. There are no persistent focal abnormalities or epilepsy form features.*
>
> *The clinical semiology of the facial twitching together with the surface EMG recordings would be most in keeping with very brief contractions (and would do for focal myoclonus). The eye movements are a little more difficult to assess on video, but there are some jerky movements at times during periods of eye-opening. There is no EEG change to support an epileptic (i.e. cortical) substrate for these movements, but subcortical myoclonus is not excluded (we have seen another patient with opsoclonus-myoclonus in the context of Covid infection)."*

38. Later, on 1st February 2021, Dr B felt that she was slightly more alert, and attributed this to the L-dopa. The dose was increased to 4 mg daily. On 2nd February she was said

to show occasional tongue movements and definite signs of improvement but still no response to pain. When reviewed by Dr B on 3rd February 2021 he noted that, when she was asleep, there were no facial or eye movements, but they gradually evolved and emerged as she woke up. Her eyes opened spontaneously.

39. Dr B wrote:

> "*Not clearly obeying commands but at one point it looked like she was trying to put out her tongue to command. Ocular bobbing and slow horizontal nystagmus. Bulbar/face/tongue tremor (parkinsonian) – this is not epileptic. Flaccid quadraparesis, no limb movement spontaneously or to pain*."
>
> "*Impression: a modest but clear improvement in her neurology! I suspect this is primarily spontaneous resolution and partially (possibly) rotigotine."*

40. On 4th February 2021, she was noted not to be tracking with her eyes. There was a flicker of movement in her left finger. On the 5th February 2021 she was noted to be yawning, and to open her eyes to voices but not to make eye contact or show visual pursuit. By 7th February 2021 she was having periods without ventilatory support but "*was working hard to sustain effort"*. On 10th February 2021 there was a sudden desaturation, following a spontaneous rise in blood pressure, without any obvious stimulus. Later that day it is recorded that AH might be obeying commands.

41. On 12th February there was an EMG and nerve conduction study reported:

> *"most likely explanation of these findings is probably an ITU-related myopathy. However, fibrillation potentials can reflect innervation, and peripheral nerve pathology (possibly Covid related) remains a possibility, although the relative preservation of sensory responses, and global nature of the weakness argues against this somewhat. Whilst a primary abnormality of neuromuscular transmission would be a consideration from the neurophysiology, this seems clinically unlikely."*

Later, on the 12th, the results of the metabolic investigations were reviewed and did not show any major findings.

42. On 15th February 2021 she had a further MRI brain scan. This was reported in comparison to the previous MRI brain scan on 28 January:

> *"there are persistent areas of increased T2/FLAIR signal with restricted diffusion in the globi pallidi and substantia nigra, not significantly changed. No new areas of abnormal brain signal intensity. Previously demonstrated areas of cortical signal abnormality on the FLAIR sequence in both cerebral hemispheres are not apparent on this examination, which may be a reflection of views*

> *of the 3D FLAIR sequence at 1.5 Tesla, compared to the previous examination. No new intracranial abnormalities. No hydrocephalus, midline shift or effacement of the basal cisterns."*

43. On 16th February 2021 when seen her eyes were open spontaneously, but there was no clear or convincing response to commands. She was triggering the ventilator but needed marked pressure support. There was less autonomic instability. There was ocular bobbing, facial/mouth/jaw tremor, dystonic tongue posturing and a flaccid quadraparesis with bilateral face and jaw weakness. The MRI scan of 17th February 2021 showed non-specific bilateral symmetrical muscle atrophy and myositis of both her thighs. On 19th February 2021 she underwent a right deep perineal nerve motor branch and muscle biopsy. The reported findings at operation were of very atrophied nerves and muscle bellies with no detectable conduction with nerve stimulator up to 10 micro amps.

44. On 23rd February 2021 she was considered *"essentially static, no steps forward neurologically, eyes will open to voice, not fixing gaze for me today"*. Weaning continued. The MR scan of her pelvis did not show evidence of a fistula.

45. On 3rd March 2021 the biopsy results were reported:

> *"Both the nerve and the muscle shows severe and irreversible changes. There is little evidence of any ongoing inflammation (beyond what would be expected). In the nerve biopsy more than 90% of actions are degenerate. Given the in-excitability of the nerve at operation it seems likely that the other actions are affected at other sites in the nerve. The possibility of neuropathy (anterior horn cell loss cannot be excluded). There was no vasculitis or demyelination and the evidence for innovation was minimal.* ***To all intents and purposes the peripheral motor nerves effectively have little to no remaining function.*** (my emphasis) *Dr Allison feels that the muscle biopsy shows features of necrotising myopathy in addition to the inevitable atrophy from denervation.".*

46. On 6th May 2021, Dr A, wrote an email to his colleagues succinctly signalling his concern. Dr A is lead consultant for the Neurosciences and Trauma Critical Care Unit. He has jointly led the hospital's critical care response to the pandemic. There are very few people within the medical profession who are more familiar with the literature, epidemiology and general science relating to the Covid-19 virus than Dr A. 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. It also strikes me as a highly instinctive reaction. I emphasise that this was not foreshadowing a conclusive view on anybody's part, but it was initiating a process of enquiry which it was recognised from the start would be challenging, complex and sensitive.

47. In the email, Dr A notes that the patient did not have the mental capacity to make decisions for herself and was unlikely to recover it, and that she potentially might never recover sufficiently to live outside hospital. He wrote:

> *"We would currently offer CPR and full escalation of intensive care medicine. Our shared view is that this would be futile."*

48. He noted at the end of this long email that a meeting with the family should be convened:

> *"This discussion will include areas such as CPR and escalation but must also include a discussion about best interests and, if our opinion is that we should consider withdrawal of life-sustaining therapy, we will discuss this with the family."*

49. Following this email, a meeting was held on 18th May 2021, and the summary note suggested a continued requirement for ventilatory support and contemplated transferring AH to a *"Nippy"* ventilator to be used outside an intensive care unit. The ten people present agreed that *"escalation of care to mandatory ventilation, organ support (cardiovascular and renal replacement), and CPR would be futile and not in the patient's interests."* However, they also *"did not feel there was sufficient evidence, at this stage, that all treatment was futile and we should withdraw care."* I am bound to say that, as I follow the chronology of AH's care, I am impressed not only by the extent to which her medical needs are so carefully monitored and responded to but also by the obvious extent to which her dignity is both identified and protected.

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.

51. On 20th May 2021 AH had a further MRI brain scan. The report was

> *"the T2 hyper intensity in the globi pallidi and substantia nigra seen on the previous examination is no longer evident. There are no new foci of T2 hyperintensity. Scattered non-specific punctate foci of subcortical white matter hyperintensity and generalised mild brain volume loss are unchanged. No new foci of abnormal intracranial*

> *restricted diffusion or susceptibility artefact. A review suggested that T2 hyper intensity remained in the caudate nuclei and lentiform nucleus. There was also new T1 hyper intensity in the globus pallidus."*

52. On 18th June 2021 a referral was made to the Clinical Ethics Advisory Group concerning continued medical treatment in view of the distress that all now agreed was being very regularly experienced by AH. A referral form was completed by Dr B, and the issues identified thus:

> *i. In the absence of capacity how long should a patient endure an extremely challenging neurological state to allow her clinicians and family to reach a best interests decision?*
>
> *ii. Where the treating clinicians feel that both CPR and re-escalation of care are inappropriate. but the family are resistant, and divided, how should we come to a conclusion about her best interests?*
>
> *iii. Whilst these matters are slowly resolved, are we acting unethically in continuing to treat her which, in effect, is merely preventing her from dying from the brain injury she sustained in January?*

These simple, succinct and manifestly pertinent questions are identified in response to AH's evolving presentation. Once again, it signals to me that her needs are kept unwaveringly central at all times. It is a paradigm of good practice.

53. On 24th 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 the family members agree with this.

54. Dr B assessed AH on 2nd July 2021. His impression was

> *"less responsive to questions than before – I suspect she is distracted by the increasing realisation and is in consequence distressed. There was no evidence of recall today."*

55. On the same day she was examined by Dr A, but she became frequently distressed. He asked if she would prefer somebody speaking a different language (Punjabi is her other language), and she said no on three occasions. She indicates this by shaking her head. As has been impressed upon me, she has no way of instigating communication or identifying her own discomfort or general needs. Dr B described this in graphic terms in his evidence. He identifies it, rightly in my view, as a particularly cruel and insidious type of pain. I note that F (AH's eldest daughter) had come to a similar view, which she analysed with clarity and poise in her own evidence.

56. On 5th July 2021 AH was seen by Dr David Christmas, consultant psychiatrist. He noted that she was more interactive, but that she became less consistent with answers after a

short time. Many of the questions were not answered. He noted an episode lasting two or three minutes during which she began sticking her tongue out, curling her lips back and thrusting a jaw forward. Following the episode, she returned to her previous state.

57. I emphasise the following paragraph, not least because I re-read it to caution myself when, at the request of the family and the Official Solicitor, I visited AH in hospital:

> *"communication clearly improved from couple of months ago.* ***However, remains very difficult to be confident that I have access to a consistent mental state, even taking expected fatigue into account. She remains very inconsistent with responses to all but simple questions (e.g. are you in pain or are we in Cambridge). It is very easy for the questioner to misread yes/no/no-answer responses and it is also hard to avoid asking leading questions (despite being yes/no) as such, being confident that she is suffering a depressive episode of any severity currently is difficult to point of impossibility*** (my emphasis)
>
> *However, in her pattern of current communication and the answers she endorses suggests against a severe depressive episode which would clearly be impacting upon her communication at this time (indeed, taken at face value, she does not endorse key depressive symptoms of low mood, tiredness or lack of enjoyment). Additionally, the pattern of communication is what one would expect with limited motor control and her ancillary medical needs.*
>
> *I continue to agree with my colleagues in neurology that this lady continues to lack the mental capacity to make all but the most simple decisions (as before, in my opinion, their view here is far more expert and important here than mine). Her retention seems quite variable even the straightforward facts (e.g. she did not endorse having had Covid, but seems consistent that she is in hospital in Cambridge), when discussing more vague topics such as feelings, future et cetera she became more inconsistent to the point I did not believe we were discussing the same thing. Her communication is such that it is almost impossible to clarify she is clearly understood complex information as she will fatigue before one has confidently got through more than a few chunks of information. At present my best guess is that she does not have a depressive illness which would affect this process. Please note the caveat above, I cannot be confident here."*

He did not think that antidepressant medication or treatment should be tried.

58. On 6th July 2021, Dr B examined her and recorded

> *"obeys commands, eyes open spontaneously. No speech, some mouthing of words. Roving eye movements, less intrusive than before. Closes one or both eyes, but no obvious squint when eyes open. Tremor of face and dystonia of tongue continue (not notably worse on*

> *stopping rotigotine). Intermittent rotatory head tremor (confounds interpretation of yes no gesturing). Flaccid quadraparesis. [AH] needed to be roused and engaged in multiple points during the assessment. Used head nodding (yes) and shaking (no) for communication."*

59. He asked a series of questions (as he had done on previous occasions) and she quite frequently did not answer. She responded to being frightened and distressed. Dr B continued:

> *"during assessment [AH] repeatedly became distressed and tearful. When she answers [AH] gives correct answers more often than incorrect but struggles to stay focused for more than a minute or so. She had no recall. Struggles with more complex questions. Impression. I think [AH's] awareness is rather variable day-to-day but overall is unchanged for the last week or so. She does not have capacity for anything other than trivial questions.* ***She is suffering and distressed****."* (my emphasis)

60. This last remark is a conclusion shared by the entire medical and nursing team and by the family. 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.

61. On 7th July 2021, it was noted that AH was *"able to communicate with eyes, some neck and lips movement. No limbs moving still. She had a NIPPY ventilator. She was fed through a nasogastric tube, and catheterised. A trial of a speaking valve failed due to secretions."* I should recall that the speaking valve continues to be used though largely at the insistence of A and M. Its presence generates a sound which reminds them both and A, in particular, of their mother's now silent voice. It brings them understandable comfort.

62. Dr Chris Danbury was instructed, by the Official Solicitor, to assist both her and the Court. Dr Danbury is a Consultant Intensive Care Physician. He regularly provides expert reports for the Court of Protection and his work is well known and highly regarded. Dr Danbury agreed both with Dr B's conclusions and with his analysis. In particular, both considered that AH has four neurological or myopathic pathologies triggered in early January 2021, in consequence of the Covid-19 infection. These are:

    i) Cerebral encephalopathy;
    ii) Brainstem encephalopathy;
    iii) Motor neuronopathy, affecting the anterior horn cells or axonal degeneration;
    iv) Necrotising myopathy.

63. Both Dr Danbury and Dr B identify the high fever in early January 2021, as symptomatic and not causative of the cytokine/autoimmune 'storm' which created this devastating neurological damage and the pathological processes that I have reviewed.

A believes that this episode was in some way attributable to negligence within the hospital. For this reason, I specifically record that both Dr B and Dr Danbury have seen similar cytokine 'storms' in patients critically ill with Covid-19 although neither has seen damage as extensive as that sustained by AH. All agree that it is in consequence of this 'storm' that there has been such extensive damage to the nerves and to the muscle as well as to the brain.

64. Dr Danbury included within his addendum report a copy of the radiology performed on AH in July 2021. He attached an image from the MRI formed on AH's thighs and included an image of a normal MRI of a left thigh taken at approximately the same level, to illustrate the loss of muscle mass. All agree that it goes far beyond that seen in critical illness myopathy. It is a very striking feature of the evidence. Dr Danbury describes the muscle loss as *"massive"*. In this devastating pathological landscape, it is thought that the necrotising myopathy is arguably the most severe of the four pathologies. I am told, and there is no dispute, that there would be no recovery of the muscle, which is further compromised by the lack of nerve supply.

65. Dr Danbury postulates that the regular episodes of severe desaturation are likely to be attributable to the combination of phrenic nerve damage and necrotising myopathy effecting the diaphragm. The importance of this is that if AH is to continue on ventilation, that can only be safely achieved in an Intensive Care Unit (ICU). This in and of itself, would be highly burdensome to AH. Every family member recognises this point.

66. Dr Danbury, whilst expressing the view that his opinion is "*finely balanced"* concludes that *"it is not in [AH's] best interests to receive long term mechanical ventilation and it is in her best interests to transition to palliative care"*. I note that Dr Danbury has included within his report a schedule which seeks to balance advantages and disadvantages of the competing options. Though the attraction of such an exercise is beguiling, it is rarely, in my experience, productive. An assessment of 'best interests' must, ultimately, survey the whole landscape of a patient's medical, welfare and emotional needs. The importance of 'sanctity of life' cannot be weighed effectively, for example, against the frustration of being unable to generate communication or the unrelenting distress of an infected bed sore. They are conceptually different and therefore, to my mind, logically resistant to a balance sheet exercise. Dr Danbury's report follows the approach I have suggested. However, he incorporates the balance sheet document, comparing the competing options i.e. of continued ventilation as against a palliative regime. I include this here merely to illustrate how unsatisfactory such an approach can be. I emphasise this is not a criticism of Dr Danbury whose report is, as will be obvious from the above, wide ranging and analytical:

Advantages	**Disadvantages**
Prolongs life	Suffering may increase as she emerges into consciousness with concomitant symptoms from other pathologies
Consistent with her wishes and preferences as expressed by her family	Ventilation will not reverse the neurological or myopathic injury

Opportunity for continued recovery of neurological and myopathic pathologies	Her place of residence will have to remain an intensive care unit for safety (unless an 'at risk' discharge is planned)
Consistent with her religious beliefs as expressed by her family	Regular suctioning of the airway causing pain and distress
	Regular, inevitable respiratory tract infections
	Other infections will occur over time (e.g. Urosepsis)
	Development of pressure sores (which may then become infected. Pressure sores are extremely painful.
	Each episode of desaturation has a small risk of worsening her brain injury

67. In Re **A (A child) [2015] EWCA Civ 486** at [at paras 48-59] McFarlane LJ warned how the danger of the 'balance sheet exercise' is that it can so easily become what he termed *"a map without contours"*, which succinctly encapsulates my concern with the above. *"Prolongs life"* has, at very least, ambivalent advantage in the context of a patient who is dying and in pain; *"consistent with her wishes and preferences as expressed by her family"* has limited meaning where, as here, the family express different views and are not always consistent; *"consistent with her religious beliefs as expressed by her family"* is again rather nebulous. In any event, though it has been raised, the family has not emphasised an objection to withdrawal of ventilation on the grounds of Islamic belief. There are differing views within the family.

68. Dr A has made some key observations in his report with which all the doctors agree. It is an unusual feature of this case that whilst the way forward has been described as *'finely balanced'* every single professional involved in AH's care, has reached the same conclusion i.e. that continued ventilation is not in her best interests. There is no dissenting professional voice. I highlight this only to record the fact, recognising that it is the strength and cogency of the analysis and not the number of people who express it which calls to be evaluated. However, I also note 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.

69. **Some key facts**:

i. AH is currently being cared for in a critical care unit and is dependent on mechanical ventilation, continuous nursing care, nutrition and

hydration delivered via a nasogastric tube, and receiving various medications. Dr B described the burden of the ventilation on AH as the equivalent of being compelled to run a marathon every day;

ii. AH requires frequent suctioning of her trachea to control respiratory secretions, this is, all agree, **extremely painful** (my emphasis). She is turned frequently to avoid pressure lesions and a hoist is used to allow her to sit in a specially adapted chair. The burden of the turning means that her rest is constantly disturbed. Added to this, is the inevitable noise generated in the ICU, which I witnessed and was rather surprised by on my own visit. AH has a urinary catheter and a rectal tube to manage faeces. She is unable to move other than small movements of her head and neck;

iii. The care for a patient in this condition is, in Dr A's words *"associated with a 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. This extends from decisions of the utmost gravity, such as withdrawal of treatment, to very modest choices like whether her head faces the window so that the sun warms her, or whether her head does not face that way because the light hurts her eyes."*. I signal that, in my judgement, this weighs very heavily both in evaluating the quality of AH's existence and in assessing how she would regard her present circumstances;

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

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"* and speculates *"it is possible that she relives the discovery of her condition repeatedly"* (with respect to Dr A, whose evidence I have found to be extremely impressive, I am not prepared to follow him in that last speculation, for which I can see little, if any, forensic base);

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".*

70. In his oral evidence Dr Danbury made two very striking observations. Firstly, paying tribute to the excellence of the Addenbrooke's hospital, he doubted whether AH would have survived this far without the resources and skills that they have been able to call upon. Secondly, he told me 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.

71. In his oral evidence, Dr A confronted the reality of AH's prognosis. She has, he told me, significantly diminished life expectancy, which is now certainly less than 12 months and, though it is difficult to be prescriptive, perhaps somewhere around six or possibly nine months. 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.

72. To my mind, the identified 'delicacy' of the issues in this case arise from two important aspects of it. Both are facets of AH's core humanity. AH is able to feel and show some degree of emotion. Predominately, she now reveals pain and real distress. However, she plainly sustains comfort from the presence of her children who have been the focus of her life. I have been told that AH has also been 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. In many ways I do not consider that matters, what is more important is that she enjoys the comfort of her children being with her on these occasions.

73. A recently recorded a Koranic call to prayer, he did so in a large warehouse which enabled his strong and clear voice to resonate and echo. He asked me to listen to it and I did, once in the court room but also, on a number of occasions, privately, out of court. I found it powerful, beautiful and an extraordinary expression of filial love. A had plainly thought about this very carefully and planned it. His sincerity was evident both from his reaction when he listened to the recording in the court room, as well as in his voice as he sang the call. I was told, and entirely accept, that his mother manifestly enjoyed listening to it. Having heard all I have about AH I can think of nothing that was more likely to penetrate through her pain than this act of love.

74. All this signals to me that however depleted and compromised her life may have become, AH retains the capacity to feel and receive love. This is an important facet of human autonomy and dignity.

75. Secondly, whilst AH cannot communicate her own self-generated thoughts she can, with some level of consistency (though not completely), respond to short and focused questions. Of necessity many of these questions are what lawyers would call "leading", in the sense that they permit only of a yes or no answer. I add that I have been repeatedly advised by the medical experts that such questions are frequently accompanied by body language and expression which communicates the desired response. Invariably, this is not deliberate, it is simply human instinct. A desperately wants his mother to live. Though he has the intelligence to absorb the impact of the medical evidence, his love for his mother causes him to retreat from the force of it. He devises questions to put to his mother in which he hopes to find evidence to support his own desire that she may continue to be ventilated.

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.

77. Continuing the status quo, in the light of the above, cannot be an option. Ventilation away from the ICU, for a significant period, carries the risks that have been identified. It is simply not regarded as medically safe, given AH's pattern of desaturation. Accordingly, it would be a misleading premise to identify it as an option which preserves life, even to a vestigial degree. The reality is that it runs the real risk of an avoidable, painful unexpected death, with no family in attendance.

78. It strikes me that one of the few options created by AH's situation is that it presents a real opportunity to plan for a peaceful end to her life in circumstances which bear some semblance of those she would have wished for herself.

79. Accordingly, I turn to consider AH and her likely wishes and feelings in respect of the medical options in her present circumstances. I do so at this stage in the judgment

because I have found it necessary to set out the complexity of the medical background in order to give context to the decision with which the Court is faced. That said, I wish to emphasise that it is AH's best interests and her wishes and feelings, in so far as they can be elicited, that are in unwavering focus here. What others might want for themselves in AH's situation or what they want for her is entirely extraneous. It is only what she wants or would have wanted that is relevant.

80. There are features of AH's life which might lead some to think that she had been unlucky and unhappy. I do not consider this to be the case. I have heard much about her from her sister, T and from her children. AH had the doubtlessly traumatic experience of fleeing from a barbarous regime in Uganda with her parents whilst she was still a young child. She would have had to adapt to a country and way of life which was alien to her. I have no doubt that her experiences exposed her to racism and discrimination. When she was very young, she contracted a marriage with a man who, though not without charm (as his son A indicated to me), was irresponsible, addictive, controlling and abusive. At the second attempt and whilst her children were still young, AH escaped from him and went to live, initially, in hostel accommodation. Whether that generated in her a distaste for communal living or not, the fact is that she has regularly indicated that she did not want to live in a care home when she grew old. Each of her children highlights this, even though they may disagree on other matters. Though it is not directly relevant it has weighed on the children's minds when evaluating the available options.

81. AH managed to bring up her children in a way which allowed each of their very different personalities to blossom and flourish. K, the eldest son, is relaxed, and easy going. He told me that in the pandemic he had to move out of his mother's home, where he had lived all his life, to live in accommodation which had been organised to enable NHS workers to live in a Covid safe environment. He did this in order to protect his mother and the patients. K has been employed by the NHS in a general maintenance capacity for 15 years. I sensed that he is proud of his employment and of the NHS. Giving up his home to live in a single room alongside work colleagues for many months would be regarded by many, and rightly so, as an extraordinary personal sacrifice. It did not seem to occur to K that he had behaved in any way admirably. He regarded himself as having a job to do and simply got on with it.

82. The younger son, A is an entirely different character. Although I have no doubt that AH loves her children equally, she certainly loves A differently. He is her "golden boy". The relationship between the two is intimate, intense and interdependent. Miss Khalique QC, on behalf of the Official Solicitor, asked him when he left home. He responded that he never really did. He is in his 30's with a wife and three children and some might think this arrangement unusual. A told me that he called on his mother every day and she would cook him a meal. He would decide the menu, she would be happy to be needed. I asked him whether this created a problem with his wife, but he told me that it did not, and he spoke about his wife in fulsome and loving terms. These arrangements seem to work for all involved. Each of the children told me that as they grew older and began to drift away their mother became anxious and unsettled. There was, all agree, a certain fragility to her in the last five years.

83. The elder daughter, S, also in her 30's, now lives in Australia with her partner and her young child. From the other side of the world, she remains closely connected to her mother and siblings. Latterly and inevitably the contact has been via video conferencing

platform but during her mother's illness she has been able to fly over to the United Kingdom with her young son to see her mother. I found her to be a poised, reflective and articulate young woman. Paradoxically, I formed the impression that S's geographical distance facilitated a more objective assessment of her mother's best interests. This is not, in any way, to deprecate the other siblings it simply reflects their different situations. S considers her mother's present pain to be intolerable and avoidable and unambiguously supports the medical consensus. She is particularly troubled by the fact that her mother is unable to communicate any discomfort, pain or frustration to the outside world. Dr B's evidence in this respect plainly had a great impression on her. S was astute in identifying that her mother's emotional pain is as present as her physical pain.

84. M, the younger sister, is very close to her mother. She visits her every day in hospital and for lengthy periods. She attends to all her most intimate cares and ensures that her mother presents a good face to the world. When I attended the hospital to visit AH, M went ahead to prepare her mother. She attended to her hair and put her into a smart black cardigan. She also showed me a video on her telephone of her and her mother by the sea, I think in Turkey, in the summer preceding the pandemic. It was particularly poignant; AH was enjoying the sea and the wind in her hair.

85. M has been successful in her career. She is a highly organised young woman. In the holiday video I saw M doing everything she could to make her mother happy. On this occasion, at least, it was impossible not to notice that it was M in the caring role. This resonated, for me, with what the children have told me, albeit in general and tactful terms, of their mother's anxiety in recent years. The responsibility of caring for parents is afforded great weight and emphasis in the Muslim life and was certainly visible here.

86. I have taken a little time to describe the children here because some understanding of their individual relationship with their mother and, to a lesser extent, each other, is necessary when endeavouring to evaluate their particular perspective on what their mother would want in her present circumstances.

87. T, AH's sister, who attended (remotely) throughout, told me that she was *"struggling"* with the medical options. She had no doubt that her sister was in pain. She had, on a visit, asked her if it *"hurt everywhere"* and her sister nodded in affirmation. K was also clear in his oral evidence that his mother was in significant pain. I think that he was telling me that, at least in his view, she had a low pain threshold. Certainly, he said that she would *"not like to be in pain"*. I formed the impression that he struggled to find the right words to express himself, in part because the ethical issues are complex but also because he did not want to offend his siblings, especially A. He struck me as bowed down by the weight of having to take a proactive decision one way or another about his mother. He told me it scared him. I think he was telling me that he regarded a decision actively to stop ventilation as *"a bit of a violation"*, though even that phrase reflects ambiguity.

88. M had been absolutely clear to Professor Wade, when he interviewed her, that *"if she had asked her mother what she would want in this situation before the illness struck, she* (her mother) *would not wish to continue"*. This is no longer M's explicit position, though her conflict about her mother's welfare is almost palpable. She states that her mother's improvement in consciousness causes her to hope that she might continue to improve to a degree which makes her life (i.e. her mother's life), tolerable. She

recognises that this optimism cannot be founded in the medical evidence but contends that doctors do not know everything and that her mother may yet confound them. In many ways the fact that AH is still alive after succumbing to the corrosive cytokine storm is itself remarkable.

89. In December 2020, A contracted Covid. Though he is young and fit he was very unwell, happily he did not require hospital admission. M also had Covid and finally AH contracted it. It would have been unimaginable for A and M to leave their mother entirely isolated throughout the pandemic. They were meticulous in their precautions, but they continued to have contact. I suspect that A, in particular, feels a sense of responsibility and guilt. In my judgement he should not, and I am very clear that his mother would not want him to. They were three adults who made the best arrangements they could in an unprecedented pandemic.

90. As I have foreshadowed above, AH took great comfort from her faith. Her family were originally from Pakistan and though they moved to Uganda they were expelled, as South Asian residents, in the early 1970's. AH is fluent in Punjabi and English. Her mother is still alive, but her father died a few years ago. Family is very important to AH, she spent a great deal of her leisure time travelling around visiting relatives. K reported that his mother complied with the Islamic duty of Zakat i.e. the obligation to donate to charity. As I have already mentioned AH went on pilgrimage (Umrah) with her sister T and her son K.

91. AH has carved a strong independent life out for herself and her family. A put it thus:

> *"She is the pinnacle and a superior example of an independent woman that has broken the norm of Asian culture"*

92. AH was fond of music; I have been told jazz and piano in particular. She also enjoyed listening to Islamic prayers and cantations ('du'as'). It was no doubt with this in mind that A prepared the recording I have discussed above. AH enjoyed peace and privacy and relaxation. I am told, by M, that she also enjoyed "pampering days" at a spa. I strongly suspect that M enjoys such days herself and that no small part of her mother's pleasure was seeing M enjoy herself. It is clear that AH was a strong, quiet, private person whose family was the lode star in her life.

93. Whilst I have identified AH's religious and cultural views as integral to her character and personality, I am not prepared to infer that it would follow that those views would cause her to oppose withdrawal of ventilation in these circumstances. On these difficult end of life issues there are differing views within each of the major faiths, including within Islam. There is recognition that intervention which may have a powerful effect on the body may be antagonistic to the integral well-being of the patient. Once treatment is identified as both burdensome and futile and where death becomes inevitable, the prolongation of death is recognised as disproportionate. Some faiths perceive man as having been created in 'the image of God', from which human dignity is perceived to be established. It is therefore reasoned that the protraction of death is inimical to respect for God and thus, inconsistent with belief. The assumption that AH would have taken a particular theological position on her treatment plan solely because she is a Muslim, even an observant one, is not an assumption I am prepared to make. To do so risks subverting rather than protecting AH's autonomy. I also note that there is a range of opinion, within this Muslim family, as to what is the right course to take.

94. It has been said that AH was very sad when she heard that a colleague had died by suicide and that she considered suicide to be wrong. I agree with Ms Gollop QC, on behalf of the Trust, that this casts no light on the issues I have to decide. Ms Gollop makes the following submission:

> *"There is no evidence that [AH] would have considered others stopping her ventilation as suicide or forbidden by her faith. Clearly it is not suicide.*
>
> *[AH's] overriding value in life was family. The protection, promotion and care of her children in particular, as well as their children. Her life with them, her mother and siblings. That was everything to her."*

I agree with both these points.

95. I have already indicated that on 29th December 2020, whilst she was in hospital and experiencing pain and respiratory distress, AH completed a form known as a "ReSPECT". The exact entry has been overwritten in the course of updating. The clinical records make some rather scant reference to AH indicating that she wanted *"full escalation"* of treatment. Miss Khalique makes the following submission in respect of the document:

> *"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."*

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.

The framework of the applicable law

96. The law in this area is relatively easy to state though often, as here, intensely difficult to apply to the facts. There is no doubt that AH lacks the capacity to take her own decisions in relation to her medical treatment and nobody has sought to argue to the contrary. I need therefore say no more than that the presumption of capacity erected in the Mental Capacity Act 2005 (MCA), has been rebutted in this case. AH's best interests fall to be determined in accordance with section 4 of the MCA 2005 which provides:

> *"(2) The person making the determination [for the purposes of this Act what is in a person's best interests] must consider all the relevant circumstances and, in particular, take the following steps.*
>
> *(3) He must consider—*

> *(a)whether it is likely that the person will at some time have capacity in relation to the matter in question, and*
>
> *(b)if it appears likely that he will, when that is likely to be….*
>
> *(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.*
>
> *(6) He must consider, so far as is reasonably ascertainable—(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
>
> *(b) the beliefs and values that would be likely to influence his decision if he had capacity, and*
>
> *(c) the other factors that he would be likely to consider if he were able to do so.*
>
> *(7) He must take into account, if it is practicable and appropriate to consult them, the views of— . . .*
>
> *(b) anyone engaged in caring for the person or interested in his welfare, . . .as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).”*

97. 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."*

98. The ultimate and clearest iteration of the law remains that in **Aintree University Hospital NHS Trust v James [2013] UKSC 67**:

> *"[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."*

> *"[45] Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."* (per Baroness Hale)

99. AH's rights protected by the European Convention on Human Rights are engaged. In the present context, the relevant rights are established by Article 2 (the right to life),

Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for a private and family life). As the ECtHR recognised in **Burke v UK [2006] (App 19807/06)**:

> *"the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (see also its findings as to the compatibility of domestic law with Article 2 in Glass v. the United Kingdom, no. 61827/00, § 75, ECHR 2004-II)."*

100. In this context in **Aintree University Hospitals NHS Foundation Trust v James** (supra) at [22], per Baroness Hale highlighted the following, which seems to me to be particularly apposite in this case:

> *"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."*

101. These sentiments were re-stated in **An NHS Trust v Y [2018] UKSC 46** at [92], Lady Black delivering the judgment of the court:

> *"Permeating the determination of the issue that arises in this case must be a full recognition of the value of human life, and of the respect in which it must be held. No life is to be relinquished easily."*

Conclusion

102. The applicant Trust considers that AH has two choices. Ms Gollop frames it in these terms:

> *"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."*

103. I consider Ms Gollop has correctly identified the options. The Trust has concluded that it is the second of these that most effectively meets AH's best interests. The Official Solicitor posits an alternative option, via Miss Khalique. She suggests that AH should continue to be ventilated outside the hospital. Whilst this may appear to resolve the medical and ethical challenges that the case presents, it simply cannot be grounded in the medical evidence. Continued ventilation outside the ICU is decidedly not a safe

option, in the view of the treating clinicians. I accept that view and the reasoning which underpins it, which I have discussed above.

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.