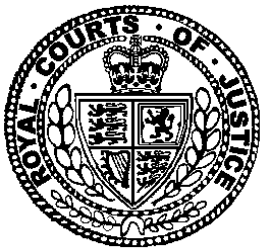

Neutral Citation Number: [2023] EWCOP 39

Case No: 1410326T

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25/08/2023

Before:

THE HONOURABLE MR JUSTICE HAYDEN

- -

Between:

GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	**Applicant**
- and -	
(1) Mrs VA **(By her litigation friend, the Official Solicitor)** **(2) VK**	**Respondents**

- -

- -

Mr Adam Fullwood (instructed by Hill Dickinson LLP**) for the Applicant**
Mr Neil Davy KC (instructed by the Official Solicitor**) for the First Respondent**
VK appearing as a **Litigant in Person**

Hearing dates: 24th August 2023

- -

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.

.....

THE HONOURABLE MR JUSTICE HAYDEN

The judge has given leave for this version of the judgment to be published.

MR JUSTICE HAYDEN:

1. I am concerned in this application with Mrs VA, who is 78-years of age and currently a patient in the ICU at a hospital. Mrs VA was taken to a hospital on the 16th February 2023, following a collapse at her home. She was discovered by the police and it was not clear how long she had been in that position. On the day following her admission, she suffered an acute drop in consciousness level with a Glasgow Coma Score of 3 i.e., the lowest: no eye-opening; verbal response or motor response. Because she was unable to manage her swallow, she was intubated and transferred to ICU. There, her condition improved and to such a degree that four days later, she was removed from ventilation and transferred, on the 24th February 2023, to the High Dependency Unit (HDU).

2. Sadly, on 26th February 2023, Mrs VA suffered several further cardiac arrests and was resuscitated and returned to the ventilator. Though she was successfully resuscitated, it took 90 minutes to achieve spontaneous circulation and accordingly, in that lengthy period, cerebral blood flow was impaired.

3. Mrs VA was weaned from sedative medication to undergo extensive investigations. Repeated EEGs, in late February and early March, demonstrated moderate injury to the brain but an MRI scan, conducted on 9th March 2023, showed small infarcts and a significant hypoxic brain injury. All clinical imaging, neurophysical images and observations are consistent with ischaemic encephalopathy following cardiac arrest. On 6th April, the Trust convened a 'Best Interests' meeting. Mrs VA's children, though invited, did not attend. A 'Do not Attempt Cardiopulmonary Resuscitation' (DNACPR order) and a Treatment Escalation Plan was put in place. On 5th May 2023, Mrs VA was reviewed by the neurology team at the hospital who concluded that clinical signs and the features of hypoxic and ischaemic brain injury shown on the MRI scan, indicated that there was no real prospect of any neurological recovery. In view of this, a further 'Best Interests' meeting was arranged. Mrs VA's daughter (W) attended but she indicated that she had no authority to speak on behalf of the family.

4. It is convenient to set out the observations of Dr H, Consultant Neurologist, in his neurological reviews over the following period:

> *"The assessment is almost 10 weeks after the period of injury (cardiac arrest)*
> *Spontaneous breathing*
> *No response to voice but opens eyes briefly and inconsistently to loud clapping*
> *Corneal reflexes present*
> *Alternating downbeat nystagmus with left beat nystagmus in the primary position*
> *VOR abnormal*
> *Apparent blinking is probably part and synchronous with the nystagmus*

To deep pain the only reaction is extension of the left toe and foot
Bilateral extensor plantars

16 June 2023 Neurology Review
Note remains off any sedating medications.
Nurses report no significant change in condition.

On examination:
Eyes open briefly a time spontaneously, not consistently, not to voice or visual threat, pain.
Some flexion of lower limbs to painful stimulus, and also some brief spontaneous nonpurposeful
flexion movements of lower limbs observed.
Triceps and knee reflexes present bilaterally
Otherwise reflexes absent.
Pupils symmetrically small approximately 2mm, no clear reaction to light. Abnormal VOR
Impression-remains in vegetative state

Addendum:
Confirmed with her there would be no merits in reimaging, as her neurological state appears
unchanged with no meaningful progress and it would not add any further information beyond
what we already have currently.

27 June 2023 EEG
The patient was off sedation. The patient was seen to spontaneously cry and blink during the
recording.
The background activity was of very low amplitude and diffusely slow. Runs of low amplitude
theta and delta rhythms were seen over the temporal regions, perhaps slightly more prominent over the left temporal region. When external stimuli were applied, subtle brain reactivity was seen.

Opinion
The EEG features suggest a moderate diffuse reactive encephalopathic state. Clinical and neuroradiological correlation is advised.

4 July 2023 Assessment by [Dr H]
Has been no significant sedation for many weeks.
No response to voice, clapping or visual threat
Eyes closed
Sluggish pupillary response
No spontaneous eye movements

> *On VOR does not go far beyond the horizontal on leftwood gaze. Limited vertical gaze.*
> *Corneal reflex present*
> *Coughs and gags on suction*
> *Breathes spontaneously*
> *No limb response to painful stimulus in cranial nerve territory seen.*
> *Suggestion of extensor tone in a flexed elbows*
> *Biceps reflexes symmetrical and a little brisk, triceps just present.*
> *No lower limb response to painful stimuli in cranial nerve territory but withdrawal response on plantar testing.*
> *Knee-jerk present plantar responses extensor.*"

5. At the conclusion of these reviews, Dr H was clear that the history, the neurological signs and all the tests and investigations undertaken, created a clear conclusion that this was a profound injury to the brain which had occurred in consequence of a predominately ischaemic insult. Mrs VA, due to her age, intermittent hypertension and diabetes had, according to the imaging, probably sustained a significant loss of cerebral substance prior to the index medical events. The predominant factor was the prolonged hypertensive ischaemic event which occurred on the 26th February 2023. As Dr H emphasised, the medical records document five discrete episodes of cardiac arrest:

> *"It is clear that even between these, relatively brief, events she was profoundly hypotensive and required relatively high doses of adrenaline to maintain her blood pressure. The mechanism of the cardiac arrest remains uncertain but is likely to have been arrhythmic in origin. The severity of the brain injury in an older patient with limited cerebral is unquestionable."*

6. The repeated clinical assessments that have been taken with regularity, now over many months, reveal a complete absence of any signs of recovery of cerebral function. Dr H expressed the following conclusion:

> *"Brainstem function remains intact and her brainstem reflexes from eye movements at the top of the brainstem to breathing in the low medulla are present. There have been no features to suggest any meaningful cortical recovery and I do not think that any recovery of cognitive function is possible. MRI imaging shows extensive white-matter change which is directly attributable to the prolonged hypotension and the complete absence of cerebral perfusion that occurred during the cardiac arrests. The EEG findings mirror the severity of the clinically apparent encephalopathy.*

> *She has been seen by at least 6 Consultant Neurologists who are unanimous in the view that, with the deepest regret, there is no possibility that this lady will make any significant improvement in her cognitive function and she will remain in her present state indefinitely."*

7. It is convenient to record here that the family do not contest the lack of any meaningful recovery, but they do not believe that Mrs VA's awareness is as profoundly compromised as the medical evidence indicates. Dr H made himself available to give evidence, at short notice, in order to answer the questions raised by the family. The family suggested that Mrs VA was aware of their presence and displayed physical responses such as moving her eyes and crying at appropriate times. I found Dr H to be measured, kind and entirely willing to engage with the family's enquiries. Mrs VA's level of consciousness has been referred to as "vegetative state". Dr H, who has not appeared before me before, spontaneously volunteered that he did not like the term. I agree with him and have said so in previous judgments. It is a phrase that, to my mind, provokes inevitable distress and resentment. It is an uncomfortable term to apply to a human being. Mrs VA is at the lowest end of the spectrum of a profound disorder of consciousness. Nothing further requires to be said.

8. Dr H was clear that Mrs VA's eye movements, tears and grimacing were all manifestations of a reflexive response. However, he very properly recognised that an absolute answer to this is, and probably always will be, impossible. It cannot be tested, it requires the disproval of a negative. Dr H was prepared to say and without hesitation, that there may be some vestigial capacity to experience both distress and sensory pleasure which may endure after conscious awareness has been lost. This is important, not least because it validates the family's experience of their mother at the end of her life.

9. On 26th June 2023, the Trust commenced these proceedings. They had been entirely unable to forge a meaningful working relationship with the family to help understand where Mrs VA's best interests lie. Having heard from the family, it is clear that they hold the Trust, in some way, responsible for the cardiac arrests that Mrs VA suffered, on 26th February 2023, whilst in hospital. They have identified no foundation for this view. It is an anger, I sense, driven by their own grief. During the course of the evidence before me, VK, the youngest daughter, found it almost impossible to focus on her mother's present circumstances, drifting back time and again, to these complaints. She is, at this stage in her life, vulnerable. She told me she has nowhere to live and is moving from place to place at the moment. Her grief is almost palpable.

10. The Trust's application sought determination as to whether it is in Mrs VA's best interests to undergo extubation and palliative care or to have a tracheostomy and PEG inserted. The Trust apparently considered, at the time of the application, that both were equally valid options. They have now revised this position. As I have commented to Mr Fullwood, who acts on behalf of the Trust, I have not found the logic which underpinned the basis for those apparently equal alternatives, easy to

identify in either the written or oral evidence. The change in the Trust's position has, unfortunately, reinforced the family's general resistance to the hospital.

11. On 3rd July 2023, a further 'Best Interests' meeting was convened at which Mrs VA's oldest daughter (MA) attended. The Trust understood that agreement had been reached at this meeting to the effect that Mrs VA should have a tracheostomy and PEG tube and as part of a ceiling of care, she should not be re-admitted to the ICU for ventilation or given other invasive organ support.

12. On 5th July 2023 the matter came before Mrs Justice Morgan. All of Mrs VA's children were notified of the hearing but none attended. The court was informed that agreement as to treatment had been reached at the 'Best Interests' meeting on 3rd July. It is highlighted that during a telephone call between MA (the eldest daughter and the de facto head of the family) and Mrs B, a lawyer in the Official Solicitor's office it was understood that MA's position, and also that of her whole family, was that they agreed that a tracheostomy and insertion of a PEG was in VA's best interests. On that basis a final order was made.

13. After the hearing had concluded VK attended court and raised objections in relation to the final order. The following day she filed and served a COP9 application requesting the order be set aside. The grounds were as follows:

> *"Order made is not in line with the facts*
>
> *No time was provided to seek legal advice or representation*
>
> *No opportunity was provided for a fair hearing providing me or other siblings with the opportunity to speak on my mother's behalf at the hearing held in the Royal Court of Justice on 5th July 2023 at 11.30am".*

14. VK made a formal complaint to the Trust which was responded to on 5th July 2023. In an attempt to help, on 12th July 2023, Dr H reviewed Mrs VA again and stated, "*I am afraid that there has been no change in her condition and my opinion concerning the absence of any prospect of meaningful recovery is unchanged."*

15. On 26th July 2023 a hearing in response to VK's application took place before Mr Justice Poole attended by VK, MA and V (the youngest son). MA advanced her disagreement with the proposed ceiling of care plan and VK said she needed more information before she could make a decision and wished to be joined as a party. She was joined and directed to confirm her position by 31st July and if not, to file an application setting out which parts of the order she objected to. Following the hearing Dr T, Consultant in Critical Care spoke with Mrs VA's children in the presence of the legal representatives of the parties, including the Official Solicitor, to provide as much further information and explanation that he could.

16. On 31st July 2023, VK filed a yet further application asking for the order of 5th July to be "*set aside, varied or revoked"* and, as she expressed it, to *"void the behavioural*

contract". She also asked for the DNACPR order *"to be removed"*. For good measure, a request was also made for more time to consider Mrs VA's condition and all options.

17. On 2nd August 2023 the matter came before Mrs Justice Roberts when directions were given for VK and other family members to file and serve statements setting out their positions in relation to the 5th July 2023 order with the Trust and the Official Solicitor to respond. On 3rd August 2023 the Trust provided a response to a list of questions raised by the family covering various issues including Mrs VA's condition, available treatment options and best interests. It is perhaps important to remember that the family are afforded extensive visiting opportunities and regularly interact with the staff. That said, nobody has visited Mrs VA for the last 8 days.

18. On 9th August 2023, VK, MA and V sent emails setting out their positions. On 14th August 2023 the Trust filed and served a further statement from Dr T and Dr C.

19. Mrs VA's children have been visiting her far less frequently in the last 6 weeks. The records show that W has visited on 13th & 20th August and V and VK visited on 16th August. I have been told that VK has no access to a laptop although she does have a mobile phone on which she can read emails. She has refused to give an address of any family or friends that she would want documents sending to. She has also said that she would refuse any documents given to her at the hospital. She has told me that she has experienced domestic violence in two relationships. It is impossible not to recognise her frailty in her evidence.

20. On 21st August 2023, MA emailed the court and the parties stating that she was a "family representative" of Mrs VA. In summary, it is said that Mrs VA would not wish to be extubated and that ceilings of care and DNACPR order are not appropriate. She states that she will be in Saudi Arabia on the date of the hearing but is *"willing to be contacted at any time to provide any further clarification"*. That language, which was reflected in MA's oral evidence, crystalises a misunderstanding in this family that the nature and extent of their mother's treatment is somehow within their gift or authority. It is not. Mrs VA has lived a full, courageous and busy life. Her present incapacity does not infantilise her. An instinctive response to look after an elderly mother does not mean that the mother's autonomy may be taken away from her. The family's role, as they have come to understand in this hearing, is to help the Court understand, to the extent that it is possible, what Mrs VA would want in her present circumstances. This can now only be understood by endeavouring to understand Mrs VA's character and personality, what she may have said, if anything, in contemplation of her current situation. The code by which she has lived her life.

21. Though the medical evidence in this hearing brought additional clarity it, inevitably, reflected the statements that had been filed. Dr C clarified that Mrs VA's brain is in a process of atrophy. She is generally weaker and her muscle tone and function is also deteriorating. She does not require mechanical ventilation or treatment in ICU. She is receiving room level oxygen and can breathe independently. Her challenge is that she

has a weak cough which could be managed effectively with deep suctioning via tracheostomy on the ward. Self-evidently, that is an intrusive procedure. Dr C, in common with all the other doctors, is clear, for reasons to which I have already alluded that treatment of any kind is, and has been for some time, futile. It is also burdensome.

22. Extubation involves a risk that Mrs VA's cough might not be strong enough, effectively to regulate her own airways. The first 24 hours would be key. If Mrs VA managed, this would permit the potential for her to be moved to a room, off the ward, for further care. If it were not successful, she would need medication to limit her secretions, less intrusive suctioning and this might not be successful. To confront the reality, it might lead to her death. As the doctors have made perfectly clear, Mrs VA is dying. Her children struggle to accept this and hope for reversal of their mother's medical fortunes.

23. As everybody in this case is aware, ICU is an incredibly busy and extremely noisy environment. This is unavoidable, it is providing intensive care. It affords little privacy and no peace. The purpose of ventilatory support is, as Dr C put it *"to support the patient whilst you identify and treat any reversible condition"*. When these are realistic objectives, the privations involved are proportionate and justifiable. When these objectives have disappeared, they are not. For Mrs VA, there is no reversible condition. Moreover, as I have already emphasised, she can breathe without ventilatory support. There can be no justification at all for continuing ventilation.

24. As Mr Davy KC, on behalf of the Official Solicitor and Mr Fullwood, properly identify, the issue in this case is whether Mrs VA should undergo insertion of tracheostomy and PEG tube or simply be extubated. This is the 'best interests' decision to be taken in this case.

The Law

25. The law in this sphere is settled and relatively easy to state. The application of it, however, is always intensely difficult involving, as it invariably does, the intersection of ethics, medicine, the law and, not infrequently, religious belief.

26. In *Burke v General Medical Council* [2005] EWCA Civ 1003 [2006] QB 273 the Court of Appeal described the general position as follows:

> *"(i)* ***The doctor, exercising his professional clinical judgment, decides what treatment options are clinically indicated (i e will provide overall clinical benefit) for his patient****. (ii) He then offers those treatment options to the patient in the course of which he explains to him/her the risks, benefits, side effects, etc involved in each of the treatment options. (iii)* ***The patient then decides whether he wishes to accept any of those treatment options and, if so, which one****. In the vast majority of cases he will, of course, decide which treatment option he*

> *considers to be in his best interests and, in doing so, he will or may take into account other, non-clinical, factors. However, he can, if he wishes, decide to accept (or refuse) the treatment option on the basis of reasons which are irrational or for no reasons at all. (iv) If he chooses one of the treatment options offered to him, the doctor will then proceed to provide it. (v) If, however, he refuses all of the treatment options offered to him and instead informs the doctor that he wants a form of treatment which the doctor has not offered him, the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (i e he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion." (emphasis added)*

The court's role where a patient lacks capacity to consent to medical treatment

27. Lord Stephens, in *A Local Authority v JB* [2021] UKSC 52 [2022] AC 1322, described the relationship between the MCA and the Court of Protection as follows (at [47]):

> *"The MCA defines the powers of the Court of Protection. In essence the Court of Protection has the power to decide whether a person lacks capacity to make decisions for themselves, and, if they do, to decide what actions to take in the person's best interests."*

28. Baroness Hale, in *Aintree v James* [2013] UKSC 67 [2014] AC 591, described the questions for the court as follows:

> *"18. ...[The court's] role is to decide whether a particular treatment is in the best interests of a patient who is incapable of making the decision for himself.*
> *...*
> *19. ... Generally it is the patient's consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment...*
> *...*
> *22. [T]he focus is on* ***whether it in in the patient's best interests to give the treatment, rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it****..." (emphasis added)*

Presumption in favour of approving life-sustaining treatment powerful but not absolute

29. There is no obligation on a patient with decision-making capacity to accept life-saving treatment, and doctors are neither entitled nor obliged to give it. As set out by Lord Brandon in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1:

> *"a doctor cannot lawfully operate on adult patients of sound mind, or give them any other treatment involving the application of physical force ... without their consent', and if he were to do so, he would commit the tort of trespass to the person"*

30. In *Aintree v James* [2014] AC 591 at §§35 – 6 Baroness Hale stated as follows:

> *"35. The authorities are all agreed that* ***the starting point is a strong presumption that it is in a person's best interests to stay alive****. As Sir Thomas Bingham MR said in the Court of Appeal in Bland, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy".* ***Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.***
>
> *36. The courts have been most reluctant to lay down general principles which might guide the decision.* ***Every patient, and every case, is different and must be decided on its own facts.*** *As Hedley J wisely put it at first instance in Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as Bland, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time." (emphasis added)*

31. In *North West London Clinical Commissioning Group v GU* (Rev1) *[2021] EWCOP 59*, I made the following observations:

> *[63] Though it is an ambitious objective to seek to draw from the above texts, drafted in differing jurisdictions and in a variety of contexts, unifying principles underpinning the concept of human dignity, there is a striking thematic consistency. The following is a non-exhaustive summary of what emerges:*

> 1. *human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
> 2. *an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;*
> 3. *human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*
> 4. *thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
> 5. *the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*
> 6. *compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.*
>
> *[64] Thus, whilst there is and can be no defining characteristic of human dignity, it is clear that respect for personal autonomy is afforded pre-eminence. Each case will be both situational and person specific. In this respect there is a striking resonance both with the framework of the Mental Capacity Act 2005 and the jurisprudence which underpins it. The forensic approach is 'subjective', in the sense that it requires all involved, family members, treating clinicians, the Courts to conduct an intense focus on the individual at the centre of the process. Frequently, it will involve drilling down into the person's life, considering what he or she may have said or written and a more general evaluation of the code and values by which they have lived their life.*

Best interests

32. Where a person is unable to decide for himself, there is an obligation to act in their best interests: s.1(5) MCA 2005.

33. Where a decision relates to life-sustaining treatment, the person making the decision must not be motivated by a desire to bring about death: s.4(5) MCA 2005.

34. When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence their decision if they had capacity, and to the other factors that they would be likely to consider if they were able to do so: s.4(6) MCA 2005.

35. Account must be taken of the views of anyone engaged in caring for the person or interested in their welfare: s.4(7) MCA 2005.

36. Carers, including health professionals, are permitted to carry out acts in connection with personal care, health care, or treatment of a person who lacks capacity to consent: s.5 of MCA 2005. It provides a significant degree of protection from liability, provided that the act is done in the reasonable belief that capacity is lacking and that the act is in the person's best interests.

37. The provisions of ss.15 to 17 MCA 2005 give the court power to make decisions about personal welfare and to make declarations and orders in respect of a person who lacks capacity. Section 15 deals with declarations, including declarations as to the lawfulness or otherwise of any act which has been or is to be done. Section 16 enables the court, by making an order, to make personal welfare decisions for a person without capacity, and, by section 17, the court's power in this regard extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care.

38. Section 16(3) MCA 2005 makes it clear that the court's powers under section 16 are subject to the provisions of MCA 2005 and, in particular, to section 1 and to section 4. What governs the court's decision about any matter concerning personal welfare is therefore the person's best interests.

MCA 2005 Code of Practice

39. The MCA 2005 Code of Practice ('**the Code**') issued under s.42 MCA 2005 came into effect in April 2007. Chapter 5 of the Code titled '*How should someone's best interests be worked out when making decisions about life-sustaining treatment?'* includes the following guidance:

> *"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".*
>
> *"5.33 ... 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"?*
>
> *"5.38. In setting out the requirements for working out a person's 'best interests', section 4 of MCA 2005 puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests ..."*
>
> *"5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)"*

The Family's evidence

40. Mrs VA came to the United Kingdom from Nigeria aged 25 years of age. She qualified as a midwife and brought up six children, largely on her own. She was plainly a focused and determined woman. All the family agreed, with smiles that were rare in this sad case, that MA, the eldest daughter, was most like her mother. That had become obvious, even before it was articulated. MA regularly intervened, out of order, notwithstanding that she was appearing remotely from Saudi Arabia. At one point, it was she and not me who decided in which order the family should give their evidence. I emphasise that I was amused and not in any way offended. Even she realised she was being rather bossy. Her manner, her style, her strength of character, her eloquence and intelligence brought a great deal of her mother into this courtroom.

41. MA, who perceived herself as spokesperson for the family, felt that extubation and palliative care would be perceived, in her culture, as a family giving up on their mother. The siblings nodded in agreement as she advanced her argument. In this

family however, the siblings have various degrees of identification with their culture and/or religion. MA, who appeared in niqab from Saudi Arabia plainly has a much stronger identification with her Muslim faith than the other siblings, who have different lives and experiences. Mrs VA was also quite eclectic. V particularly remembers her enthusiasm for "Songs of Praise". This sense of responsibility and deep-seated belief in their duty to their mother has, in my judgement, paradoxically, diverted their focus onto what they think might be the right thing to do and not, as it should be, what is in their mother's best interests.

42. Mrs VA's parenting style differed from child to child. VK was, on her own account, rather a handful and her mother set rigid boundaries. MA was plainly recognised as second in command and V, the youngest son, was joyfully indulged. Each of these children return their mother's love fulsomely. As they have matured, they told me that they have appreciated how incredibly strong and independent she was. She embraced the UK but remained a "proud African woman", as MA described her. Part of that pride involved having a strong sense of privacy. She found particular solace in the space of her own home. V lived there until his early 30s. He told me, in a gentle way, that he had struggled to break free.

43. Because each of the children had different relationships with their mother, they have struggled to engage with the challenge of wondering what she would have wanted in her present parlous position. Some families never have the discussion about what they would want if they were to be in Mrs VA's circumstances. It could happen to anybody and the experience of this Court is that many do have such conversations. Increasingly, people make Advance Decisions setting out what their wishes would be. This family did not have these kind of discussions. MA said that it was not in their cultural tradition to do so. In any event, I am satisfied that Mrs VA never approached the subject.

44. Mrs VA complied with some of her medication and not with others. I am told that she rather disliked hospitals and had an anxiety about professional negligence. Though I guard against the family's understandable strain to filter evidence into their own concluded view, I think this is most likely correct. It fits with the wider evidence of Mrs VA's intellectual independence.

45. None of this provides secure ground to establish what Mrs VA would have wanted. That said, I am clear that privacy and independence were both important to this courageous woman.

46. To justify continuing the invasive procedure of the tracheostomy, deep suctioning and PEG in circumstances where there can be no medical benefit and only physical burden, I would have to be satisfied that this is what Mrs VA would really have wanted. Even then, her wishes and feelings would not be determinative.

47. Mrs VA is dying. She has a chance of doing so in the relative privacy and peace of the ward, perhaps even in a nursing home. With luck her children may share that privacy

with her. Within the narrow ambit of what can be done, this is a not insignificant change for her. Extubation, palliative care focusing on giving Mrs VA the best quality of life, at the end of her life, is, I find, what is in her best interests. Accordingly, I grant the declaration sought by the Trust. It is important that I emphasise that the Official Solicitor who has attended personally throughout this hearing supported the Trust's application, having heard all the evidence.