



Neutral Citation Number: [2023] EWCOP 46

Case No: 14075103

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25th August 2023

Before:

THE HONOURABLE MR JUSTICE HAYDEN

Between:

**NORTHERN CARE ALLIANCE NHS
FOUNDATION TRUST**

Applicant

- and -

**(1) KT
(By his litigation friend, the Official
Solicitor)**

(2) JO

(3) GT

Respondents

Mr Vikram Sachdeva KC (instructed by Hill Dickinson LLP) **for the Applicant**
Miss Fiona Paterson KC (instructed by Official Solicitor) **for the First Respondent**
Miss Francesca Gardner (instructed by Stephensons Solicitors) **for the Second Respondent**

Hearing dates: 23rd 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. This application is brought by the Northern Care Alliance NHS Foundation Trust (“the Trust”), in respect of KT, aged 53. On 25th February 2022, KT was undergoing dialysis for end-stage kidney failure when he suffered a large left-parietal intracranial haemorrhage. Sadly, despite undergoing emergency surgery, KT was left with significant brain damage. He has remained an inpatient at a specialist neurosurgical unit where he receives life-sustaining treatment, including haemodialysis and Clinically Assisted Nutrition and Hydration (CANH).
2. KT is in a “prolonged disorder of consciousness”. The compelling medical consensus establishes that he has no awareness and no scope for rehabilitation. He may have vestigial capacity to experience discomfort and distress and, at least theoretically, some ability to be soothed by his environment. It must be emphasised that this does not equate to awareness. As well as chronic Stage 5 kidney failure, KT also has co-morbidities, namely, Type 2 diabetes mellitus, diabetic retinopathy, and hypertension. His life expectancy is now very limited. The primary pathology, as Mr Sachdeva KC, who appears on behalf of the Trust, has properly emphasised, is KT’s renal failure. As I have said, he is dependent on haemodialysis three times a week to keep him alive. However, safely dialysing him has become increasingly challenging as his blood pressure tends to drop during dialysis, carrying a risk of yet further brain injury, cardiac arrest, or heart attack. The Trust seek a declaration that it is lawful to receive palliative care only. Should this course of action be followed, it is likely KT would die in consequence of renal failure within two weeks.
3. KT’s wife, JO, and his sister, GT, oppose the Trust’s application. Their opposition is shared widely within family, some of whom have joined this hybrid hearing from Canada and Nigeria. They are a family of strong Pentecostal Christian faith. They have a fundamentalist belief, both in the power of prayer and in the potential for miracles. This extends to a confidence in the power of God to cure the sick, however parlous their circumstances may be. Prior to his diagnosis with kidney failure in 2017, KT was a pastor in the Netherlands. He had always been an active member of the Church. There are recordings of some of his sermons. I have watched them, at the family’s request, and read the transcripts. I had been told that he was a very highly regarded and popular preacher. Before seeing the videos, I had only seen photographs of KT in hospital in his highly compromised circumstances. The contrast is very stark. In the videos, I saw KT as the man who he had been. He was charismatic, gentle, and manifestly committed to his Pentecostal beliefs. In his role as Pastor, he was inevitably proselytising his faith. I emphasise this because it is a clear marker of the depth of his convictions. KT’s family feel that his faith was such that he would want his life to be sustained for as long as possible, in whatever circumstances and whatever the challenges. While they do not proactively dispute the clinical evidence as to prognosis, the family feel he has a greater level of consciousness or awareness than that described by the Trust. It must be said, however, that their foundation for this view, though instinctive, is on their own account, somewhat limited. They instinctively feel that KT is aware of their presence when they visit him in hospital and say they have, on occasion, observed meaningful signs of responsiveness from

him, including his eyes following their movements and his hands shaking, they believe in response to music.

4. It is against this background that it is necessary for the court to consider the evidence and to resolve what is in KT's best interests.

The Legal Framework

5. There is no evidential issue between the parties, nor could there be, that KT lacks capacity to take his own decisions in relation to medical treatment. The presumption of capacity under the Mental Capacity Act 2005 (MCA) has therefore, inevitably, been displaced in this case. The court is consequently required to consider what is in KT's best interests having regard to Section 4 MCA 2005, which reads as follows:

“(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).”

6. The MCA 2005 Code of Practice provides:

“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.”

7. The clearest explanation of the test remains that of Baroness Hale in *Aintree University Hospital NHS Foundation 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.”

8. KT'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), [2006] ECHR 1212:

*“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).”*

9. In this context in *Aintree University Hospitals NHS Foundation Trust v James* (supra), at [22], Baroness Hale highlighted the following:

“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.”

10. 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.”

The evidence

Medical

11. Evidence on behalf of the Trust was provided by members of the multi-disciplinary team who have assessed KT and evaluated his prognosis. Mr B, a Consultant Neurosurgeon, and KT’s lead consultant at A Hospital since his admission on 25 February 2022; Dr A, a Consultant Nephrologist; Dr C, a Consultant in Neurorehabilitation. Dr J, Consultant in Palliative Care Medicine at the hospital, also provided evidence as to the end-of-life care plan for KT should life-sustaining treatment be withdrawn.
12. KT has a long-standing history of diabetes mellitus type II and hypertension. He was diagnosed with end-stage kidney failure in February 2017, for which he is dependent on haemodialysis three times a week. On 25th February 2022, whilst undergoing haemodialysis at Manchester Royal Infirmary, he became less responsive and developed a right-sided weakness. A CT scan revealed that KT had suffered a large haemorrhage to the left temporoparietal region of his brain. He was transferred to a specialist hospital for emergency surgery. Following surgery, on 15th March 2022, he was fitted with a tracheostomy during his stay on ITU, which remains in place. Over the following three months, KT suffered complications in the form of recurrent hydrocephalus (a build-up of fluid on the brain) and an infection, which exacerbated the brain damage caused by the haemorrhage. Since then, Mr B has told me in evidence, KT has remained, at least from a neurological standpoint, stable. However, there has been no significant improvement in his condition, and there is nothing in his imaging to suggest that there is anything that surgery could improve.
13. Dr C’s assessment of KT is that he is in a prolonged disorder of consciousness with no awareness nor any scope for rehabilitation. In her most recent witness statement, Dr C explains that KT’s level of responsiveness has declined. During her most recent visits, KT was unrousable and therefore presented as being in a coma, which is in contrast to earlier reviews when he would open his eyes. However, Dr C’s is clear that in her view, KT has never demonstrated any meaningful responses, even at earlier reviews. At her most recent review of KT, Dr C recorded the following:

“I reviewed [KT] on 1st August 2023. My clinical note is as follows:

Reviewed on B8, where he is cared for in a side room with door open so that he remains visible at all times. Presents with

eyes closed & unarousable to touch, passive limb movements & sound.

Religious music playing on a CD player. No localisation to sound observed. Abnormal breathing pattern throughout my visit. Respiratory rate was approximately 16 breaths per minute however he had apnoeic spells lasting 15 to 18 seconds throughout my visit, followed by more rapid breaths. This is a poor prognostic sign & is due to central apnoea, which is indicative of additional brain stem dysfunction. I observed occasional eyelid flickers, but no eye-opening [KT] had repeated twitching movements involving the right side of his mouth which were involuntary & not in response to any external stimulus. His left arm occasionally twitched for approximately 30 seconds. My impression is that this is tonal rather than seizure activity. I also observed him yesterday at approximately 2.15pm from outside his room whilst I was on B8. A renal nurse was with him & haemodialysis was in progress. He was unresponsive with no eye opening. His left forearm was twitching spontaneously without external stimulus as I observed today. He again presents as being in coma. The disordered breathing pattern is indicative of progression of brain stem dysfunction.

4. During my most recent reviews of [KT], he has been unrousable and therefore presenting as being in a coma. This is in contrast to earlier reviews where he opened his eyes, either partially or fully. However, in my opinion [KT] has never demonstrated any meaningful responses even at earlier reviews.

5. My clinical opinions and my views on best interests, as set out in my previous witness statements, have not changed.”

14. In addition to this complex medical picture, Dr C has confirmed, from the neuroimaging, progressive brain atrophy leading to derangement of the functioning of the brain and encephalopathy. The significance for this in the future is its impact on the brain stem and the inevitable compromise of both breathing and swallowing. It requires to be confronted, as Dr C did, honestly but sensitively, that this generates the spectre of a potentially awful death. She agreed that it had been equated with drowning.
15. KT continues to receive haemodialysis three times a week for four hours for his stage 5 chronic kidney failure. Dr A explains that successfully dialysing KT has become increasingly challenging as his blood pressure now has a tendency to become low during dialysis. This is likely due to a weakening of his heart functioning, which is a

recognised problem for patients on long-term dialysis, especially when they also have a long-standing complications of high blood pressure or diabetes. A sudden drop in blood pressure carries a risk of causing further brain injury, heart attack or cardiac arrest, so it is necessary to modify the dialysis by suspending the fluid drainage while continuing to drain the waste product. This has, from time to time, resulted in KT experiencing fluid retention or intermittent swelling. Dr A explains that it is likely that at some stage later this year, the Trust will be unable to successfully complete dialysis for KT due to his blood pressure becoming too low, leading to fluid accumulation. This will cause KT to experience significant swelling which may become uncomfortable for him. It could also lead to fluid in his lungs, causing breathlessness and discomfort. The risks of dialysis for KT are such that in Dr A's opinion, if treatment were to continue, it is highly likely that at some point between now and March 2024, a complication will occur during dialysis which will result, dramatically, in his death.

16. Furthermore, KT cannot remain indefinitely on the acute ward at the hospital's neurological unit and would have to be transferred to a nursing home. He would, therefore, need to be transported from the nursing home by ambulance three times a week to have dialysis in hospital, leading to discomfort, increased risk of pressure sores, respiratory infections and dislodgement of the tracheostomy. If the tracheostomy dislodges, this would be life-threatening as KT cannot maintain his own airway and would suffer respiratory arrest within a few minutes. He would require emergency replacement of the tracheostomy tube by a specialist nurse or doctor. Receiving haemodialysis at the nursing home would now not be possible given his clinical complexity.
17. The Trust's multi-disciplinary team share the view that it is in KT's interests to stop receiving life-sustaining treatment and to receive palliative care only. As Dr B describes in his first witness statement, "*his best interests would not be served by an uncontrolled death associated with acute issues, for example, during dialysis or relating to heart failure or fluid overload.*" He explains that while the Trust are unable to prevent KT's death, they "*can potentially control and manage the process leading up to his death and enable him to have his family around him when he passes away.*"
18. Dr J has outlined a hypothetical end-of-life care plan for KT. The family have expressed the view that they would like KT to remain in hospital. This is simply not possible nor is it desirable. KT is acutely vulnerable to hospital-acquired infection. His exposure to that is inevitable but can be limited. His tracheostomy would remain in situ. KT's death would likely be brought on by the consequences of his renal failure due to withdrawal of dialysis rather than withdrawal of CANH. This would likely occur within two weeks. Appropriate use of palliative care medicines would prevent any pain or suffering. Psychological and spiritual support would be provided to the family by the specialist palliative care team, the palliative care social worker and the spiritual team in the hospital.

19. The statements from the Trust set out the minutes of two meetings which the medical team have had with KT's family, on 2nd September 2022 and 11th November 2022, to discuss the future management of his treatment. However, the family were unable to reach an agreement with the clinicians as to what would be in his best interests. Whilst there is disagreement between the family and the Trust, there is a respectful understanding by each of their respective positions.
20. The Trust has sought second opinions from Professor Wade, a consultant in neurological rehabilitation and Professor Mitra, a consultant nephrologist.
21. Dr Wade visited KT in hospital on 21st December 2022. During his visit, he met JO, GT, and KT's other family members via Microsoft Teams. He agreed with Dr C's assessment that KT is a prolonged disorder of consciousness with no evidence of awareness and only limited responsiveness. He explained that if, against his expectation, KT were able to experience anything, his overwhelming experiences would be ones of discomfort and pain. In his view, any further investigations into KT's condition would be unnecessary. He did not consider there to be a prospect of any significant, sustained improvement, and estimated that KT's life expectancy would be, as of December 2022, under a year. His view is that it would not be in KT's best interests to continue with active medical treatments. Professor Wade states the following in his report dated 23rd December 2022:

*"7.5 I have concluded that he is in a prolonged disorder of consciousness, now with no evidence of awareness and only limited responsiveness. Second, there is no need for any further investigations, assessments of his clinical state, rehabilitation interventions or assessments, and there are no treatments. **There is no prospect of any significant, sustained improvement. His life expectancy is about one year, determined by his chronic kidney disease.***

*7.6 Based on his clinical situation and what I have been told about him, **I do not think it is in his best interest to continue with any active life-sustaining medical treatment.**" (emphasis added)*

22. Professor Wade, who is one of the country's most experienced experts in this sphere told me in evidence that of the many patients with prolonged disorders of consciousness that he sees, KT is in the bottom few, in terms of level of consciousness; somewhere between 2nd and 5th per centile.
23. As Professor Wade noted, Professor Mitra, Senior Consultant Nephrologist, explained in his report that dialysis would not be commenced in patients under the same clinical circumstances as KT, namely in a prolonged disorder of consciousness with no scope of rehabilitation, in view of extremely poor short-term prognosis. Dialysis was continued in KT's case as he was a pre-existing dialysis patient, however, the

circumstances are no different. In Professor Mitra's view, continuation of KT's dialysis is inappropriate and futile, and adopting a palliative approach would be in his best interests.

The Family

24. KT's sister, GT, has provided a statement which is said to also represent the views of his wife, JO. In it, she explains that KT is a Christian and previously a Pastor in the Church of Holland. While the family did not have a conversation with KT previously about what he would want to happen to him in his present situation, GT explains that her brother's beliefs were so strong that they are confident that he would want treatment to continue. She explains that KT "*believes that death is only [to be] an act of God and that we should not interfere with that.*"
25. KT is described by his sister as "*a fighter.*" GT recalls two different incidents when KT was in seemingly desperate clinical situations but where, against all odds, he was able to pull through and survive. Despite having kidney failure since 2017, KT, I am told, would never let it get him down. He spent his free time researching different treatments, as he was resolved and determined to live as long as possible. GT believes that KT would "*want to know that everything possible had been done*".
26. As I have foreshadowed, the family do not dispute the medical evidence as to KT's diagnosis or prognosis; however, they do say that his level of awareness is higher than that described by the clinicians. GT says that the last few times she has visited KT, he has been "*fully awake*", with his eyes open. She describes seeing signs of meaningful responsiveness. She has seen his face changing in pain while JO massages his feet and she says that she and JO often play music while they visit KT and dance in his room and describes seeing KT's hands shake in response to the music.
27. GT describes the family's strong Christian faith and their belief that "*death should happen for us all when our time comes and should not be hastened*". She also explains that they believe that more research should be done into KT's condition and possible solutions.
28. The family have provided a letter from the Pastor from KT's Church in the North of England. It describes KT as a man of "*stubborn faith*". I have noticed a certain stubbornness of faith in other family members. I emphasise that I do not state this as a criticism. The letter describes KT as a man who believes in the "*supernatural power of God*". It also states that KT is "*strongly against the practice of withdrawing any form of treatment from a sick person just because the medical team believe that the person is not improving*".
29. They have also provided two emails from friends of KT from Holland. The first email attests to KT's strong faith in God and describes him as a resilient man who "*does not believe in giving up*". There is, in my assessment, much evidence of that. The second email describes KT as being against euthanasia due to his view on the sanctity of life. It says that KT was a man who stood by his promises and was prepared to pay a high

price to hold onto his personal convictions; from this it is inferred that KT would not abandon his commitment to the sanctity of life even when confronted with pain and his own death. It is also said that KT believed in the power of “*bouncing back*” after setbacks and “*with the help of God.*”

30. I have no doubt that I saw a family deeply rooted in Pentecostal beliefs for whom their faith was integral to their everyday life. They believe that KT has already experienced miracles. KT’s popularity as a Pastor is, in my view, not only because he was a charming and engaging personality, but also because his faith was so evidently genuine and sincere.
31. I find that KT’s attitude to his faith, the way it drove his life and its uncompromising nature, as has been identified, leads me to have confidence in the family’s view that he would not have wished his life to be brought to an end in the circumstances the Trust consider meet his best interests. He would rather suffer and hold out for the will of God. He, I accept, was a strong anti-abortionist and strongly opposed to a lay version of euthanasia. This reinforces his likely attitude to his present circumstances. He was, I find, a man who lived his life by the Pentecostal sword and most likely would have wanted to die by that same sword i.e., in accordance with his Pentecostal beliefs. Though neither the Official Solicitor nor the Trust shares my assessment of this, I have, I confess, had little difficulty in arriving at this conclusion. Though he may never have had the conversation about end of life with any of those who have spoken with me, the code by which he lived his life is pellucidly clear and, in my judgement, reflected by his family.
32. Whilst an individual’s wishes and feelings weigh heavily in evaluating their best interests, they are not to be regarded as determinative. On this point, on the framework of the law, there is agreement amongst the advocates. The weight to be afforded to perceived wishes and feelings, varies from individual to individual. Mr Sachdeva has provided a convenient summary of the law which is both helpful and uncontentious and I can adopt it. I have found that KT would have wanted continued life-sustaining treatment, even in the face of a coma with a terminal diagnosis of chronic kidney disease stage 5. It is plain from examining the terms of the Mental Capacity Act that the weight to be placed on any particular factor is a question for the court.
33. As Mr Sachdeva emphasises, the statute itself does not lay down that beliefs and values or wishes and feelings are determinative. The jurisprudence did not lead to any other conclusion.
34. In *Re M (Statutory Will)* [2009] EWHC 2525 (Fam) [2011] 1 WLR 344 at [35] Munby J, as he then was, said the following:

“First, P’s wishes and feelings will always be a significant factor to which the court must pay close regard: see Re MM; Local Authority X v MM (by the Official Solicitor) and KM

[2007] EWHC 2003 (Fam), [2009] 1 FLR 443, at paras [121]-[124].

Secondly, the weight to be attached to P's wishes and feelings will always be case-specific and fact-specific. In some cases, in some situations, they may carry much, even, on occasions, preponderant, weight. In other cases, in other situations, and even where the circumstances may have some superficial similarity, they may carry very little weight. One cannot, as it were, attribute any particular a priori weight or importance to P's wishes and feelings; it all depends, it must depend, upon the individual circumstances of the particular case. And even if one is dealing with a particular individual, the weight to be attached to their wishes and feelings must depend upon the particular context; in relation to one topic P's wishes and feelings may carry great weight whilst at the same time carrying much less weight in relation to another topic. Just as the test of incapacity under the 2005 Act is, as under the common law, 'issue specific', so in a similar way the weight to be attached to P's wishes and feelings will likewise be issue specific.

Thirdly, in considering the weight and importance to be attached to P's wishes and feelings the court must of course, and as required by s.4(2) of the 2005 Act, have regard to all the relevant circumstances. In this context the relevant circumstances will include, though I emphasise that they are by no means limited to, such matters as:

a) the degree of P's incapacity, for the nearer to the borderline the more weight must in principle be attached to P's wishes and feelings: Re MM; Local Authority X v MM (by the Official Solicitor) and KM [2007] EWHC 2003 (Fam), [2009] 1 FLR 443, at para [124];

b) the strength and consistency of the views being expressed by P;

c) the possible impact on P of knowledge that her wishes and feelings are not being given effect to: see again Re MM; Local Authority X v MM (by the Official Solicitor) and KM [2007] EWHC 2003 (Fam), [2009] 1 FLR 443, at para [124];

d) the extent to which P's wishes and feelings are, or are not, rational, sensible, responsible and pragmatically capable of sensible implementation in the particular circumstances; and

e) crucially, the extent to which P's wishes and feelings, if given effect to, can properly be accommodated within the court's overall assessment of what is in her best interests."

35. In *Re G (TJ)* [2010] EWHC 3005 (COP) Morgan J stated as follows (at [55]):

"The best interests test involves identifying a number of relevant factors. The actual wishes of P can be a relevant factor: s 4(6)(a) says so. The beliefs and values which would be likely to influence P's decision, if he had capacity to make the relevant decision, are a relevant factor: s 4(6)(b) says so. The other factors which P would be likely to consider, if he had the capacity to consider them, are a relevant factor: s 4(6)(c) says so. Accordingly, the balance sheet of factors which P would draw up, if he had capacity to make the decision, is a relevant factor for the court's decision. Further, in most cases the court will be able to determine what decision it is likely that P would have made, if he had capacity. In such a case, in my judgment, P's balance sheet of factors and P's likely decision can be taken into account by the court. This involves an element of substituted judgment being taken into account, together with anything else which is relevant. However, it is absolutely clear that the ultimate test for the court is the test of best interests and not the test of substituted judgment. Nonetheless, the substituted judgment can be relevant and is not excluded from consideration. As Hoffmann LJ said in the Bland case, the substituted judgment can be subsumed within the concept of best interests. That appeared to be the view of the Law Commission also."

36. Nor are wishes and feelings identified as determinative or even generally determinative in the leading post-MCA authority, *Aintree v James*. The test contains a strong element of substituted judgment but it remains a best interests test: [24].

37. Further, in *IIBCC v LG* [2010] EWHC 1527 (Fam) Eleanor King J stated as follows at [39]:

"The fact that the incapacitated adult lacks the relevant capacity does not mean that his wishes and feelings simply fall out of account. The wishes and feelings of the incapacitated person is therefore an important element in determining what is, or is not, in his best interests. Where he is actively opposed to a course of action, the benefits which it holds for him will have to be carefully weighed up against the disadvantages of going against his wishes, especially if force is required to do this."

38. In *Wye Valley* [2015] EWCOP 60 Peter Jackson J stated as follows at [10]:

*“Where a patient lacks capacity it is accordingly of great importance to give proper weight to his wishes and feelings and to his beliefs and values. On behalf of the Trust in this case, Mr Sachdeva QC submitted that the views expressed by a person lacking capacity were in principle entitled to less weight than those of a person with capacity. This is in my view true only to the limited extent that the views of a capacitous person are by definition decisive in relation to any treatment that is being offered to him so that the question of best interests does not arise. However, once incapacity is established so that a best interests decision must be made, there is no theoretical limit to the weight or lack of weight that should be given to the person’s wishes and feelings, beliefs and values. **In some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due.**”*
(emphasis added)

39. In *Briggs (No. 2)* Charles J stated that the test cited by HHJ Hazel Marshall QC in *In re S (Protected Persons)* [2010] 1 WLR 1082, cited by me in *In re N (Mental Capacity: Medical Consent)* [2015] EWCOP 76, was applicable to all applications of the best interests test (at [59]):

“55. In my judgment it is the inescapable conclusion from the stress laid on these matters in the 2005 Act that the views and wishes of P in regard to decisions made on his behalf are to carry great weight. What, after all, is the point of taking great trouble to ascertain or deduce P’s views, and to encourage P to be involved in the decision-making process, unless the objective is to try to achieve the outcome which P wants or prefers, even if he does not have the capacity to achieve it for himself?

56. The 2005 Act does not, of course, say that P’s wishes are to be paramount, nor does it lay down any express presumption in favour of implementing them if they can be ascertained. Indeed the paramount objective is that of P’s ‘best interests’. However, by giving such prominence to the above matters, the Act does, in my judgment, recognise that having his views and wishes taken into account and respected is a very significant aspect of P’s best interests. Due regard should therefore be paid to this recognition when doing the weighing exercise of determining what is in P’s best interests in all the relevant circumstances, including those wishes.” *(emphasis added)*

40. In *Salford Royal NHS Foundation Trust v P* [2017] EWCOP, I made the following observations:

“v) *It is incumbent on the court fully to investigate and consider the values and beliefs of the patient as well as any views the patient expressed when she had capacity that cast light on the likely choice the patient would have made and the factors that the patient would have considered relevant or important: M v N at [70] per Hayden J, Briggs at [54] per Charles J;*

vi) Where the patient’s views can be ascertained with sufficient certainty, they should generally be followed (Briggs at [62] per Charles J) or afforded great respect (M v N at [28] per Hayden J), though they are not automatically determinative. ‘...if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life. Briggs at [62ii] per Charles J. ‘...the ‘sanctity of life’ or the ‘intrinsic value of life’, can be rebutted (pursuant to statute) on the basis of a competent adult’s cogently expressed wish. It follows, to my mind, by parity of analysis, that the importance of the wishes and feelings of an incapacitated adult, communicated to the court via family or friends but with similar cogency and authenticity, are to be afforded no less significance than those of the capacitous.’ M v N at [32] ...”

41. Apart from it being clearly unobjectionable as a matter of principle, there is clear precedent for the court finding that, even where a patient would wish to continue with life-sustaining treatment, it may not be in his best interests for it to continue:

“(a) NHS v VT [2014] COPLR 44 per Hayden J. Despite the judge finding that VT, as a religious Muslim, would wish to receive all possible treatment, and to deprive him of the opportunity to suffer would deprive him of the chance to purify his soul in preparedness for death; [20], he held that CPR would be ineffective, not of benefit, likely damaging and compromising of his dignity; [27] - [28]. His Lordship also held that admission to ITU would be wholly futile; [28].

(b) In Manchester University NHS Foundation Trust v KM [2021] EWCOP 42 Keehan J accepted that P was a deeply religious Pentecostal Christian with a deep belief in divine healing but held that continued ventilation on the ECMO machine was futile and contrary to his best interests, even though its withdrawal would result in death, owing to his almost non-existent lung function following Covid. He was not a candidate for a lung transplant even though if it had been possible it would have cured the pathology which was liable to

kill him (mirroring KT not being a candidate for a kidney transplant).

(c) In Kings College Hospital NHS Foundation Trust v X [2023] EWCOP 34 Theis J held that withdrawal of ventilation and CANH was in the best interests of 27 year old X, who was in a PVS following a car accident, despite finding that he would wish to continue treatment to be with his family, and in accordance with the Christian religious beliefs he had along with the wider family.”

42. Integral to the plan, if treatment were to continue, is that KT should be brought to the hospital three times per week to receive haemodialysis whilst he is in a prolonged and profound disorder of consciousness and dying from end-stage renal failure. The process would last three to four hours on each occasion. Dialysis can achieve nothing; it is both burdensome and futile. The mechanics of the plan put him at real risk on every journey. Even if he were to weather this discomfort for a few months longer, his progressive cerebral atrophy might so compromise his swallowing and breathing to make the plan, ultimately, grotesque to his dignity as a human being. It would require those caring for him, in my judgement, to cause harm without delivering benefit. It would inevitably cause the treating clinicians, nurses and carers, great distress. It would be wrong to expect them to absorb such a level of distress and to act in a way that would inevitably become contrary to their own principles. I have heard sufficient of KT to know that he would be the last person to want to impose such a burden on anybody else. Robust and uncompromising though his beliefs have undoubtedly been, it is plain from all I have heard and read that he was both a kind and gentle man.
43. Thus, the options are really limited. I have ultimately concluded that the application sought by the Trust is well-founded and in respect of which, on a proper analysis, having regard to all the factors that I have laboured to evaluate, there is, in truth, no alternative. I can tell KT, that everything possible had been done. I do, however, think that the family would want to say their goodbyes directly to KT and that he too, had he contemplated such a situation, would want that. Family was plainly important to him. Accordingly, I have concluded that to enable the family to arrange flights, I can properly, and in KT's best interests, yield to their alternative suggestion, made by Ms Gardner, Counsel for GT, that the order can be extended to 21 days from today's date. I signal that I do not consider it would be appropriate to go beyond this period and I indicate that I do not anticipate receiving any such application.