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Case No: COP13673437

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26/05/2021

Before :

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

- -

Between :

UNIVERSITY HOSPITAL BIRMINGHAM NHS FOUNDATION TRUST	**Applicant**
- and -	
AI	
(by his litigation friend, the Official Solicitor)	**1st Respondent**
- and -	
K	**2nd Respondent**

- -
- -

Mr Rhys Hadden (instructed by **Bevan Brittan LLP**) for the **Applicant**
Ms Sarah Simcock (instructed by **the Official Solicitor**) for the **1st Respondent**
K (litigant in person)

Hearing dates: 26th May 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 immediately following the hearing, the Court sitting remotely by video conferencing platform. 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 children and members of their 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.

Mr Justice Hayden :

1. I am concerned with AI, a 48 year old man, who is approaching the end of his life and in respect of whom the applicant Trust seek a declaration that it will be both lawful and in his best interests to discontinue any further attempts to provide dialysis.

2. AI was born on 22nd March 1973. He has a history of Schizophrenia and had been under the care of the community mental health team for some time. He lives in supported accommodation. He was diagnosed with end stage kidney disease ("ESKD") on 30th September 2019. He has required long term haemodialysis to remain well but has only intermittently accepted treatment. It is his fixed delusional belief, in consequence of his Schizophrenia, that there is nothing wrong with his kidneys and that he does not need dialysis. AI has also expressed delusional beliefs that the hospital is stealing his blood and that he is accruing a large bill for his treatment that he is unable to pay. This causes him great agitation. AI's mental capacity has been formally assessed, on a number of occasions, and he has been found to lack the capacity to make a decision to accept or refuse dialysis. It is axiomatic that these intrusive delusional beliefs prevent AI from weighing and evaluating the advantages of treatment. No party at this hearing has sought to dispute the fact that the presumption of capacity has been rebutted.

3. AI was previously admitted to hospital on 20th July 2020 due to his failure, in the community, to dialyse. He had last accepted dialysis on 30th June 2020. He spent some time on the ICU before being transferred to the Renal ward at Queen Elizabeth Hospital. He thereafter received haemodialysis (HD) twice per week, verbally refusing each time but when the nurse arrived at his bedside, he would passively let them connect him to the machine using his dialysis line. No sedation or restraint was required. During his admission AI was, inevitably, subject to a standard authorisation granted under the Deprivation of Liberty Scheme (DoLS). Throughout the admission AI consistently stated that if he were to be sent home he would not voluntarily return for dialysis.

4. On 22nd July he was reviewed by Dr Drubha Bagchi and it was his view that depression was impairing AI's capacity. The plan was made to start citalopram and escalate the dose over the next few days. On 3rd of September AI was again reviewed by the liaison psychiatry team (Dr Siddiqui, staff grade in psychiatry), it was his view that AI remained delusional and continued to lack mental capacity to refuse dialysis.

5. The stage was therefore reached when AI was physically well enough to be discharged but continued to state that he would not attend his outpatient dialysis appointments. It was the clinical view that it was in his best interests to be discharged back to his care home and thereafter not be compelled to attend for treatment but instead to be treated 'reactively' (see below). The family, who have given evidence before me today, took the view that AI should be compelled to attend and to receive dialysis. This would have involved physical and/or chemical and was not, in the view of the treating clinicians, reconcilable with AI's welfare interests. I agree.

6. An application was therefore made to the Court. An order was made, by Theis J, on the 23rd November 2020, in the terms the Trust sought, namely:

> *1. AI lacks the capacity to:*
> *(a)conduct these proceedings;*
> *(b)to make decisions about his treatment in relation to dialysis for End Stage Kidney Disease;*
>
> *2. Notwithstanding AI's lack of capacity to consent thereto, it is lawful and in his best interests for him:*
>
> *(a)to be discharged from Queen Elizabeth Hospital in accordance with the discharge and transition plan set out in the second witness statement of Dr Stringer;*
> *(b)to receive reactive treatment for dialysis for End Stage Kidney Disease in accordance with the Care Plan dated November 2020 ("the Care Plan") and summarised;*
> *(c)not to be compelled to receive dialysis by means of physical, mechanical or chemical restraint.*

7. AI was discharged from the hospital on the 16th December 2020. He received 11 planned sessions of dialysis, attending voluntarily, but then did not attend again from the 12th January 2021. The arrangement has been described, by Mr Hadden, who appears on behalf of the applicant Trust, as a "reactive" one. By this he has explained to me there was an arrangement in which a vehicle was sent to AI's home on the day dialysis was required and it had been left to him whether he would comply or not.

8. As his health deteriorated in consequence of the discontinuance of dialysis, AI became seriously unwell and was therefore readmitted to hospital on 20th January 2021. He remained in hospital until the 9th February 2021 during which period he cooperated with dialysis.

9. Following discharge AI attended only two sessions as an out-patient. For the avoidance of doubt there was no attendance after 13th of February 2021. In what had become a pattern, AI once again deteriorated physically, leading to emergency readmission on 23rd February 2021. He remained an in-patient until 16th March 2021. He attended 2 further sessions as an out-patient but stopped attending again from the 20th March 2021.He was consequently readmitted to hospital and again received dialysis as an in-patient between 29th March 2021 and 30th March 2021. After discharge he then attended three sessions as an out-patient but stopped on 8th April 2021. He was then readmitted from the 17th to 22nd April 2021 when he, once again, compliantly received dialysis as an in-patient.

10. Though compliance with dialysis in the community had, thus far, been desultory, this occasion marked a significant change. AI did not attend at all as an out-patient. Inevitably, he quickly deteriorated and was once again readmitted. On this occasion AI received dialysis as a compliant inpatient between the 4th May and the 9th May 2021. Again, following discharge AI did not attend any further appointments whilst living in the community. He was readmitted to hospital on the 18th May 2021. Thus, it is clear that a cycle of poor compliance with the reactive offer of dialysis, had given way to

non-compliance, whilst in the community. Non-compliance had led, in each of the above circumstances, to fluid volume overload, which in turn resulted in AI becoming severely breathless.

11. When AI was admitted on the 18th May 2021 (at 23:00hrs) with breathlessness, he, whilst in the Accident and Emergency Department, declined any medical intervention except oxygen. He was admitted to the ward and commenced emergency dialysis at 4am on 19th May. He had a chest x-ray which showed progressive fluid in the lungs and around the lungs. On the 19th May he was seen by Dr Jenny Pinney, Consultant Nephrologist, on her morning consultancy round. Dr Pinney had been involved in AI's care since his diagnosis in September 2019. She told me in evidence that she was struck by the extent to which he had physically deteriorated since she last saw him in 2020. There was significant weight loss and AI now appeared very frail. He was requiring oxygen and was very short of breath. His blood test results revealed anaemia but there were no signs of infection. He agreed to have a further dialysis session during the ward round. He commenced dialysis at 3pm. At 17:18hrs while on the dialysis machine he pulled his tunnelled line out. 3 litres of fluid had been removed during that session. There was no overt bleeding at the time. AI remained in a parlous condition. The short time on the dialysis machine fell a long way short of what he required.

12. On the 20th May 2021, on the morning ward round, Dr Pinney asked AI if he would let them insert a new line. He steadfastly and unambiguously declined. AI remains, I am told, very short of breath and swollen. The short session of dialysis on 19th May did not have sufficient impact to remove excess fluid, built up as a result of the lack of treatment since 8th May. To remove this fluid would require ongoing daily dialysis for 4 hours per day for two if not three weeks.

13. The medical staff persisted, and AI ultimately agreed to insertion of a temporary line, on 21st May 2021, to facilitate relief of some of his symptoms. This was inserted without the need for sedation and AI was successfully dialysed via the temporary line. Provided the line remains patent and in situ, it can safely stay in place for 7 to 10 days.

14. On the evening of Saturday 22nd May 2021, Dr Peter Hewins, Consultant Nephrologist, and Senior Responsible Clinician for the hospital saw AI, on his rounds. He was sufficiently concerned to send Dr Pinney the following email which requires to be set out in full:

> *"Dear all, having seen AI this evening I think there is a need to appreciate that the clinical picture is evolving and that events could well overtake us as his condition deteriorates. Despite reinsertion of a temporary dialysis line and a successful 4h dialysis session yesterday during which fluid was removed, today's dialysis has proved considerably more problematic. There has been prolonged bleeding from the groin were the dialysis line was inserted. During today's HD session, he received blood and platelets in attempt to manage the blood loss, but he remained moderately hypotensive and dialysis had to be discontinued. Post dialysis despite application of compression dressings to the groin, bleeding continued, and we were obliged to remove the dialysis line to achieve haemostasis (which appears to have been successful). AI is, however, still in pulmonary oedema meaning that there is an excess of fluid in his lungs which is*

causing significant breathless and leaving him dependent upon supplemental oxygen via a face mask (which he has kept on). He is markedly enfeebled and still appears agitated and distressed.

What will happen from here on is uncertain. Low blood pressure during and after dialysis is a comparatively common occurrence in some patients and often recovers as fluid redistributes between vascular and extravascular compartments in the body (ie blood volume expands as fluid moves from tissues into the blood stream and blood pressure then improves). Notably however, AI has not exhibited intradialytic hypotension before and in fact he was taking BP lowering medications until today due to high BP. The abrupt onset of low blood pressure and consequent infeasibility of removing fluid during dialysis may signify a significant deterioration in his condition. In simple terms, it may indicate onset of heart failure which would portend a significant and irrevocable deterioration in his overall condition. There is no immediate evidence of another reversible pathology such as infection, but we are treating him with antibiotics as a precaution. Although he may stabilise over the next 24-48h, there is also a significant risk of death.

At best, if his BP stabilises then we may be in a position to insert another temporary dialysis line into the groin and repeat dialysis sessions in the hope of getting him to the point where he is well enough for a new tunnelled line to be inserted. Unless another tunnelled line is place, AI would not be able to leave hospital but the likelihood of being able to achieve this is significantly uncertain. It is not exceptional for us to subject patients to potentially painful and distressing medical procedures in the context of what can prove to be very limited longevity but ordinarily, we are doing this with their explicit consent and in the context of the physician providing guidance on what is proportionate and reasonable for that individual. Where in the physician's judgement the risks of harm and futility are disproportionately high, we would counsel the patient and their next of kin accordingly against pursuing treatment and direct them towards appropriate palliation.

Accepting that AI is a severely vulnerable individual who is unequipped to articulate his wishes in any detail and that he lacks formal capacity to consent, the pattern of his behaviour since he started dialysis in October 2019 and specifically over recent months has been consistent in that at no point has he attended dialysis for a sustained period with sufficient regularity to have any prospect of maintaining physical health. The tipping point in these situation is often difficult to define and whilst we have put in place a ceiling of care and a DNACPR decision which will provide safeguards to ensure AI is managed appropriately if he deteriorates in specific ways, based on his condition this evening, I am still significantly concerned that we are in danger of pursuing inappropriate efforts to re-establish

> *dialysis without any realistic likelihood of durable benefit after the point when treatment should be fully focused on palliation."*

15. Though AI lacks capacity to take decisions in respect of his treatment, substantially in consequence of his Schizophrenia, this does not mean that his wishes or feelings do not require to be evaluated. On the contrary, they remain integral to his autonomy, which this court is charged to protect (see: **SS v London Borough of Richmond Upon Thames & Anor [2021] EWCOP 31**). AI has consistently been resistant to cooperating with dialysis. When he is physically weak and struggling to breathe, his response is passively to cooperate and then to disengage when he feels sufficiently restored.

16. Behaviour, when assessed carefully, may sometimes communicate feelings more effectively and accurately than words. Indeed, it may sometimes contradict what is said. AI has gradually reduced even his superficial cooperation with dialysis when in the community. Initially limiting it to twice, on two separate occasions, and finally to non-compliance (which was always his stated position whilst in hospital). On his most recent admission he withdrew the tunnel line, as I have recorded above. This was an unprecedented action. I was also told by Dr Pinney that it would have been painful. I note too that this has occurred at a time when AI has deteriorated very significantly. It is difficult not to draw the most obvious inference that he has become tired by the effort of the dialysis, which has been made much more difficult by the pattern of non-compliance, followed by urgent medical treatment. Whilst his belief system may be delusional, his exhaustion is real. The signal is, to my mind, that he has had enough. Interestingly, when describing AI's personality, his brother in law (R) told me that he had always been fastidious about clean and smart clothes but latterly had, he implied, become neglectful of and disinterested in, his appearance.

17. Dr Pinney told me that the view of her Department, including that of Dr Peter Hewins, was that if no further dialysis was administered AI would likely last a maximum of 2 to 3 weeks, though potentially a shorter period. The process of dialysing him might in and of itself precipitate collapse and death. This risk would be further increased if sedation were required, given AI's already repressed respiratory system. Respiration is also compromised as a result of the kidney failure itself. Thus, this is assessed as a real risk. Additionally, the indicators of the onset of heart failure may *"portend a significant and irrevocable deterioration"* which generate the possibility of heart failure during the course of dialysis. If AI collapsed and died in these circumstances, he would do so in a room in which several other patients were receiving dialysis. I was told that he struggles to achieve a comfortable position whilst receiving dialysis, due to his breathing difficulties and that dialysis itself can be uncomfortable and extremely tiring. Were he to "crash" as Dr Pinney put it, it would be extremely distressing, not least to the other patients. AI would not have the comfort of his family around him. Relatives are not permitted in the dialysis suite. From what I have learnt of AI, entirely from his family, he would wish them near him, if possible, at the end and he most certainly would not want to cause distress to others.

18. AI is far more than his symptoms, diagnosis or medical history. Nothing of his temperament, personality, life or character emerged in any of the records or documents presented to the court. When the Court is considering the best interests of a protected party, it will do so only by having regard to welfare in the widest sense: who the individual is; what his interests are; what is important to him in life and, to the extent that it might be possible to determine, what his values and beliefs are. These will, in

conjunction with the medical history and physical symptoms, illuminate what is most likely to be in P's best interests.

19. A narrow concentration on the medical facts and diagnostics, without evaluation of the broader canvas of an individual's life will rarely, if ever, be satisfactory. The Court of Protection has emphasised this approach in what is now a substantive body of case law. Over the course of the pandemic I have been told by several senior doctors that they have had conversations with patients over these last difficult months which have been far more extensive and candid than had formally been the case. More than one has said to me *"these are the kind of conversations we should have been having all along."* This sharper focus on understanding the personality and character of the individual patient assists decision making in the hospital every bit as much as in the court room. If I may say so, with diffidence, it strikes me that good forensic medicine and clinical medicine are one and the same. For the avoidance of doubt, I do not intend any of the above to be read as a criticism of the doctors in this case. On the contrary, they have been diligent, thoughtful and kind.

20. To remedy the identified evidential gap, I asked the family to give evidence first. K, AI's older brother, gave the primary evidence. The younger brother (S) contributed but had limited English. AI's brother in law, R, also gave evidence. He and his wife, AI's sister, were in the hospital by his bedside. AI was drifting in and out of sleep and had not spoken today.

21. The family's evidence delivered the following facts. AI and K grew up in Pakistan, in the beautiful province of Rawalpindi. Both men returned there periodically. I noticed that the sad and anxious faces of all the family members attending court (remotely) became wreathed with smiles when they discussed their village. AI was described as sociable, *"joking with everybody"* and a *"joyful person"*. K said that his brother's mental health difficulties only descended when he was about 20 years old. He considered that his brother's condition, at least initially, was relatively well managed.

22. AI has been married twice. Both marriages were arranged. Both, sadly, ended in divorce. AI has a son from his first marriage, now in his very early twenties, and two children from his second marriage. K considered that AI's mental health deteriorated considerably after the collapse of his first marriage. It was obvious that AI's family has a very strong sense of its own identity. They are strikingly supportive of each other, respectful of seniority and each is very protective of AI. They told me that he has been a very hard-working man, working long hours at a plastics factory as a machine operative. He very much enjoys the outdoors. He watches television, particularly sports and current affairs. R said that AI *"liked fresh clothes and shoes"* and also liked *"nature"*. AI reads and enjoys music. I was told he particularly liked spiritual Pakistani songs. Though he is now physically diminished and *"nutritionally very poor"*, he has, in the past, taken great pleasure in food. R told me he enjoyed Masala fish, lamb curry, two of his favourite dishes. Recently, K became a grandfather. The family told me that AI was delighted. He greatly loved his nephews and nieces and his affection was reciprocated. AI attended all family events.

23. Throughout their accounts, the family did not speak of AI's mental health problems, depression or even his kidney failure. This was in part because I had encouraged them to tell me more about him as a man. But I also sensed a family who had come to terms

with AI's conditions, tried to navigate around them and not permit them to eclipse his true personality.

24. As I have said in other judgments, the applicable law in this area is relatively easy to state. The challenge is always to apply it to individual circumstances in this highly fact sensitive jurisdiction.

The Law

25. Identifying the best interests of an incapacitated person is to be determined in accordance with s.4 MCA 2005 the key parts for these purposes provide:

> *"(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)."*

26. Applying these provisions in **Aintree University Hospital NHS Trust v James [2013] UKSC 67** Baroness Hale stated:

> *"[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."*

27. There can be no doubt that the physical deterioration seen initially by Dr Pinney and latterly by Dr Hewins is reflected in AI's diminished zest and enthusiasm for life. K sees a man whom he considers to be fitter and stronger than the doctors assess. I am afraid this is wishful thinking on K's behalf. Whether his life, without dialysis, endures for three weeks or whether, if dialysis is restored successfully, it extends to *"weeks or months"*, the reality is that AI is at the end of his life. This is not therefore a question of whether AI can fight to live, rather it is one of determining how, over what period and in what circumstances he dies.

28. The Trust has prepared an outline palliative care plan. Dr Peter Hewins has been largely responsible for formulating it:

> *"1) Anticipated survival if no further dialysis administered cannot be precisely predicted but likely to be around 2-3 week maximum and potentially shorter.*
> *2) Symptom control as required. Patients with end stage kidney disease experience varying symptoms after withdrawal of dialysis. Typically they become progressively more sleepy and will eventually fall into a coma before passing away. Pain is uncommon. The following symptoms can be managed by anticipatory medications given orally, by intermittent subcutaneous injection or by subcutaneous infusion via a syringe pump. It is not uncommon to use opioids (eg alfentanyl), benzodiazepines (eg midazolam) and antisickness medication (eg levomepromazine). Oxygen may also help:*
>
> > *a. Breathless may ensue, in part dependent on how much fluid is consumed relative to any residual urine output*

b. Itching is not uncommon
c. Nausea +/- vomiting can arise

3) Continued hospitalisation versus discharge to a hospice or home/family member. Most people state a preference at home but the practicalities of achieving this are often problematic. In principle, AI could leave hospital .

a. Given his coexisting mental health problems and the increasing end of life care needs, I do not foresee that discharge to his usual residence would be feasible. it would likely lead to emergency re-admission via 999 and the emergency department which would distressing and inappropriate.
b. He could in principle go to a relative's home and have input from a hospice team. Medications as outlined above can be provided at home. The emotional and physical undertaking involved are considerable and often prove too much but it would be appropriate to support this course of action if the family were keen to pursue
c. He could be referred to a hospice for EoL (end of life) admission – subject to hospice place availability (would remain in QEHB until transfer)
d. He could remain at QEHB and we would manage his EoL care here with support from onsite palliative care team"

29. The family has been asked by Ms Simcock, instructed by the Official Solicitor on AI's behalf, about their choice in the various options contemplated. Given that they have been opposed to the plan, it is understandable that they have not been able to engage with the various options to date. When I met with AI, on the video conferencing platform, with his counsel, AI nodded vigorously at the suggestion he might go home with his brother K. The care plan notes that such arrangement is a considerable *"emotional and physical undertaking"* but it would be supported by the hospital if that was the course they wished to take. I am confident that I can now leave the detailed formulation of the arrangements to the Trust and the family.

30. I consider that AI is tired and consistently indicating that he does not want further dialysis. I am satisfied that reinstating dialysis at this stage creates significant risk, given the identified deterioration. I note the evidence that sedation increases risk when attempting to restore dialysis. Finally, the recent abrupt onset of low blood pressure and the consequent infeasibility of removing fluid during dialysis indicate the futility of and disproportionate risk involved in restoring dialysis. AI requires peace, rest, the presence of his family and the prescribed palliative medication referred to in the care plan. This, in my judgement, conveys dignity to him at the end of his life. No other plan could achieve this. Accordingly, I endorse the care plan and grant the declaration in the terms sought.