Neutral Citation Number: [2024] EWCOP 55 (T3)

Case No: COP 20003009

IN THE COURT OF PROTECTION

Date of Decision: 20 September 2024
Date of Published Judgment: 2 October 2024

Before :

MR JUSTICE POOLE

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Re CD (Treatment: Haemodialysis)

Between :

EAST AND NORTH HERTFORDSHIRE NHS TRUST **Applicant**

- and -

(1) CD (By his litigation friend, the Official Solicitor)
(2) EF
(3) GH **Respondents**

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Peter Mant (instructed by Capsticks LLP) for **the Applicant**
Adam Fullwood (instructed by the Official Solicitor) for **the First Respondent**
The Second and Third Respondents in person

Hearing date: 20 September 2024

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This judgment was delivered in public but a transparency order is in force. 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 CD and members of his family must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Poole :

1. CD is a 66 year old married father of four and grandfather of two, who is currently cared for as an in-patient at a hospital ("the hospital") operated by the Applicant NHS Trust ("the Trust"). CD lacks capacity to conduct this litigation and proceeds by his litigation friend, the Official Solicitor. EF is his son, GH his daughter. They have been joined as parties on their application. EF and GH purport to express the views of the whole family about CD's treatment and best interests.

2. CD is of Bangladeshi origin. He has end-stage renal disease, ischaemic heart disease, type 2 diabetes, vascular dementia, and has suffered recurrent strokes. He receives haemodialysis at the hospital, now twice weekly. Each session, if completed, takes up to about four hours. His brief medical history is that he was diagnosed with type 2 diabetes in 2010. From 2016 he developed progressive diabetic kidney disease. He had a heart attack in 2018 and a stroke in 2019. In September 2022 he electively started haemodialysis but three months later he had a second stroke resulting in a significant deterioration in his cognitive function. After an initial period of unconsciousness, he spent a long time in hospital recovering before being discharged to a nursing home. The family told me that he temporarily lost his vision after the second stroke but this improved. His kidney management was transferred to the hospital because of difficulties performing haemodialysis. In his confused state CD became resistant to it. The family agreed that a family member would attend the hospital whenever CD underwent dialysis to try to reassure him and reduce his agitation. The clinicians at the Trust have paid tribute to the family's dedication in supporting CD through dialysis and more generally when they visit him, as they frequently do as a family, bringing home-cooked Bengali food with them. EF and GH told me that prior to his strokes, CD worked as a taxi driver and before that in catering. He has always enjoyed good food and the company of his family and continues to do so. He has a particular soft spot for his youngest daughter, now 16. He lights up when she and his other family members including his grandchildren enter his room. He enjoys stroking her hair. He also enjoys singing to himself.

3. For dialysis to be performed the patient requires a catheter to be inserted. A temporary catheter may be used for a short number of days but for long term dialysis a tunnelled catheter is required, which is fixed in situ. On 6 June 2024 a crack was identified in the plastic exit lumen of CD's long term dialysis line. An attempt was made on the ward to replace a tunnelled dialysis catheter under local anaesthetic but CD was too agitated for this to be performed and so replacement was achieved when he was put under general anaesthetic on 7 June 2024. He was discharged to the care home on 15 June 2024 but the following day suffered a new brain haemorrhage and infarct. He was then an in-patient for about a month. It seems that following his strokes, CD has now lost his ability to speak English but can converse in Bangladeshi using the dialect he was brought up with and which his family members can also speak.

4. Having returned to his nursing home, on 29 July 2024 CD pulled out his tunnelled catheter and was readmitted to the hospital where he remains. He has attempted to pull out his catheter on a total of four occasions since his third stroke in mid-June 2024, and this despite having 1-1 nursing and other protective measures (such as placing hospital mittens on his hands). On two occasions a catheter could be reinserted under local anaesthetic. On a third occasion clinicians decided that it would be unsafe to attempt

further insertions under local anaesthetic. so it was performed under general anaesthetic.

5. The last occasion when CD pulled out his tunnelled catheter was on 1 September 2024. A temporary catheter was inserted under sedation in theatre but by then the Trust had taken the view that further insertions of long term catheters were contrary to CD's best interests.

6. The Trust seeks the following:

   i) A declaration under s15 of the Mental Capacity Act 2005 ("MCA 2005") that CD lacks mental capacity to make decisions about his care and medical treatment; and

   ii) A decision under s16 of the MCA that:

      a) It is not in CD's best interests to have a new haemodialysis catheter inserted under heavy sedation or general anaesthetic or to receive any further haemodialysis (through the current temporary catheter or otherwise);

      b) It is in his best interests to receive care and treatment in accordance with a palliative care plan filed with this application.

7. On 20 September 2024 I heard evidence in person from Dr A, Consultant Nephrologist at the Trust who has had conduct of CD's care and treatment for his kidney disease, and remotely from Dr B, Consultant Anaesthetist and Patient Safety Lead at the Trust. I also heard evidence in person from EF and GH. Dr B was able to join the hearing remotely at short notice and told the Court about the significant risks to CD from undergoing general anaesthetic. Dr A was a most sensitive and thoughtful professional witness who impressed me with the care he has taken to spend time with CD and to reflect on his best interests. EF and GH also impressed the Court with their courtesy and insight.

8. The declaration as to capacity is not opposed. All agree that CD lacks capacity to conduct this litigation and to make decisions for himself about his care and medical treatment. I have had full regard to the written evidence provided in the hearing bundle and medical records. I need not burden this judgment with a detailed review of the evidence on capacity. I have had full regard to MCA 2005 ss1-3. It is quite clear, as all agree, that CD lacks capacity to conduct this litigation and to make decisions about his care and medical treatment.

9. At the conclusion of the hearing on 20 September 2024, I announced my decision on the Trust's application regarding CD's best interests and told the parties that I would provide a written judgment giving full reasons as soon as I was able.

10. The legal framework governing the Court's decision on CD's best interests is found in MCA 2005 s4 and the MCA Code of Practice. S4 provides:

> "(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—

(a) the person's age or appearance, or

(b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

(2) The person making the determination 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.

(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(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—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(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).”

11. The Code of Practice states at paragraph 5.31:

> "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."

12. Case law emphasises the strong presumption in favour of sustaining life but that presumption is not absolute. In *Aintree v James* [2013] UKSC 67, [2014] AC 591 Baroness Hale said at [35] and [39]

> [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.

> [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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

13. The written and oral evidence about CD's condition, treatment and future treatment options was not disputed by the family members. The family strongly disagree with the conclusions reached by the Trust about CD's best interests but not with the medical evidential basis for those conclusions. Dr A, Consultant Nephrologist, explained that although some colleagues consider it unethical to insert a new tunnelled catheter and he personally does not believe it to be in CD's best interests to do so, he would carry out the procedure if the Court declared it to be in his best interests. In the event that the Court declined to make the decision sought by the Trust, counsel jointly invited the Court to provide clarity for all concerned by making a declaration that the insertion of a tunnelled catheter for the purpose of dialysis was in CD's best interests, rather than to leave that question open.

14. The Trust has arrived at its position after an internal review by Dr B, an external review by Dr L who is an independent professional from another NHS Trust, and advice from the Trust's Clinical Ethics Group. I am quite satisfied that the Trust has adopted a considered position after a thorough process.

15. There can be no dispute that the temporary catheter must be removed. It should have remained in place for five days, seven at the very most, but was inserted as long ago as on 5 September 2024. The use of a temporary catheter creates a significant and cumulative risk of infection and sepsis which could be immediately life-threatening to CD. That specific risk could be avoided by either inserting a tunnelled catheter (which brings its own risks) as the family think is in CD's best interests, or by removing the catheter and not replacing it, as the Trust think is in CD's best interests. No-one has suggested that it could be in CD's best interests to continue with a temporary catheter or to insert another temporary catheter which would itself need to be replaced in a few days.

16. The professional evidence to the Court is that haemodialysis is preserving CD's life. If it were to stop it is expected that he will die within two weeks or so, receiving palliative care. It would be likely to be a peaceful death. With haemodialysis his life expectancy is probably between 3-6 months possibly a year but Dr A said it was more likely that CD would survive only to the lower end of the range of 3-6 months. His death then might follow an agreed cessation of haemodialysis and the introduction of palliative care, or it might follow a complication of his kidney disease.

17. CD's co-morbidities are currently stable. I understand that the interaction of his kidney disease and co-morbidities would eventually be likely to cause a heart attack or infection so as to end his life.

18. In order to undergo haemodialysis CD will have to have a tunnelled catheter inserted, most likely through the chest wall and into the internal jugular vein, because of the lack of alternative viable sites, and most likely under heavy sedation or general anaesthetic because he will not otherwise tolerate the procedure. The procedure carries risk to him of infection and bleeding together with risks associated with heavy sedation or general anaesthesia. Dr B advised the Court that there was a 10% chance that CD would die under general anaesthetic because of his co-morbidities, and a further 10% chance that he would suffer a significant complication such as a further stroke. But the Trust accepts that heavy sedation or general anaesthesia would not be so unsafe that they should not

be administered if the insertion procedure and further dialysis was considered to be in CD's best interests. The procedure takes a relatively short time – it is not major surgery. The patient typically has some moderate pain around the site for a few days. CD might well suffer from confusion, even delirium on coming round from anaesthetic or heavy sedation. Restraint might be required to administer the sedation or anaesthetic effectively and safely.

19. A further risk, in CD's case, is that, once inserted, he will disturb or even pull out the catheter as he has previously done (now four times). Ordinarily a catheter should remain in situ and functional for at least a year. The Trust believes that the stage has come at which it cannot be said to be in CD's best interests to keep inserting haemodialysis catheters only for them to be plucked out. When CD removes a catheter he puts himself at risk of significant blood loss, infection, and the need to expose him to further risks from another procedure to re-insert. If he were to pull out the catheter when undergoing dialysis it could be catastrophic, causing an immediate threat to his life from haemorrhage.

20. CD suffers from agitation intermittently. It may be that the presence of a tunnelled catheter itself sometimes causes him agitation or that he becomes confused about why it is there. That is why he has pulled catheters out. However, he also becomes agitated due to other interventions. He has become agitated and aggressive, even biting staff, when staff have tried to check his blood sugar or on the medication round. He spits out oral medication not, I expect, because it causes him pain or discomfort to take it, but because of some confusion in his mind. This is due to his dementia and poor cognition.

21. The risks of insertion under heavy sedation or general anaesthetic are significant but if the procedure goes to plan and the risks do not materialise (which is probable) it is not a major burden for D to endure, even in his confused state. It does not compare to the burden of undergoing a limb amputation or prolonged invasive ventilation.

22. The Court must also look at the utility of re-insertion. Insertion is necessary for haemodialysis which, in turn, is essential to help to preserve CD's life. I acknowledge that preservation of CD's life on successful dialysis will probably be for no longer than a few months. Nevertheless, that is a material difference compared with a period of about two weeks without dialysis. I must look at the benefits and burdens to him of his life if it is to be preserved by continuing dialysis. He would have the burdens of undergoing continued haemodialysis, now twice a week for up to four hours. It is right to record that he has found it difficult to complete dialysis, struggling to continue for the full four hours. However, he has successfully done so on the last two occasions. The process does not appear to be painful for him but it is very tiring and can cause some exacerbation of his confusion. His dementia and poor cognition appear quite often to cause him agitation after three hours or so of dialysis. On previous occasions, for example on 10 September 2024, he could not tolerate dialysis for the full procedure and it ended 30 minutes early after agitation. After that a decision was taken to reduce dialysis to twice a week from three times. The family have agreed to that reduction. Members of his family are always present at dialysis to support and calm CD. They will continue to fulfil that role.

23. As noted, CD shows agitation, even aggression, at times other than when he is undergoing dialysis. This is, I am quite satisfied on the evidence, due to his dementia and the effect of his strokes combined with the need for nursing care and interventions

including even oral medication. CD suffers from various co-morbidities and these will add to the burdens of his continued living. He will probably remain an in-patient so long as he remains alive.

24. These then would be the burdens of CD's continued life. On the other hand, the family say and Dr A accepted, CD can show joy in the company of his family. Dr A also says he has experience of CD smiling when engaging with a professional carer. He also appears to enjoy singing and sings quite a lot. He enjoys the Bangladeshi food his family members bring when they visit. As he comes to the end of his life CD experiences a mix of burdens and benefits.

25. I was told that some capacitous patients with CD's degree of kidney disease decide to bring haemodialysis to an end and to move to palliative care, others do not. The burdens of treatment are not such that no-one who could exercise a choice for themselves would choose to continue with dialysis.

26. EF and GH told me of the importance to CD of his Muslim faith, in particular over the past five to six years. He practised his faith, attending Mosque and going on pilgrimage. They said that, like all the family do, they expect that had CD retained capacity to make decisions about his care and medical treatment, he would have discussed matters with the family and, if he thought it necessary, he would have taken advice from Islamic scholars. His faith, they said, involved an acceptance of life's hardships as part of God's plan. There were limits to what a person should tolerate and they did not believe that he should, or that he would have wanted to, continue to live with intolerable burdens. But, they said, overall his current life has meaning and is worthwhile to CD. He continues to enjoy aspects of his life which sit alongside the hardship and burdens that he suffers. They told the court that they believe that CD's views would have led him to want to carry on living even through his current discomfort and distress.

27. GH told me that after his second stroke, when he was in a very poor state and it was thought he might no recover and might die, CD said to her that he wanted to live and not to die. The family told me that CD has always sought out and complied with treatment. Attempts to engage CD now in discussion about treatment choices have not shed light on his current wishes and feelings. It is not possible to discern his actual present wishes and feelings about undergoing further treatment including insertion of a catheter because he cannot think through all the benefits, risks and disadvantages, or communicate his views, but his family are all of the same view, namely that he has a quality of life such that re-insertion of a catheter and continued dialysis are merited.

28. An important factor in this case is that CD has repeatedly pulled out his catheter. Measures have been taken to try to prevent that from happening including the provision of hospital mittens and 1 to 1 care. I am sure that all steps would be taken including strapping and mittens to keep any catheter now inserted out of CD's reach or grasp. Nevertheless there is a very real risk that insertion could be rendered ineffective by CD pulling out the catheter. I must take that risk into account and it is a highly relevant consideration. Furthermore, the steps taken to mitigate that risk such as hospital mittens and 1 to 1 care are restrictions on CD which to a greater or lesser extent constitute burdens upon him.

29. I remind myself to consider all the principles and matters set out in MCA 2005 s1 and s4 and the relevant case law. The presumption that steps should be taken to preserve

life, the family's views, evidence as to CD's beliefs and values and his past wishes and feelings, and the evidence of the pleasures that he still derives from interactions with his family and others and from good food, weigh in favour of his undergoing the procedure and continuing with dialysis. I am cautious about finding that it is in his best interests to undergo a procedure the purpose of which he might unknowingly frustrate by pulling out a catheter, but without the insertion of a catheter his life cannot be preserved, and his life, if preserved, will continue to bring him real benefits alongside its burdens. There is no advanced decision to consider but the evidence is that CD is a man who, if he still had capacity, would not want his life to end prematurely unless its burdens became wholly overwhelming.

30. I have to try to examine the question of treatment and best interests from CD's point of view. Having considered all the evidence and circumstances, I have concluded that the burdens and risks involved in inserting a tunnelled catheter and continuing with haemodialysis, and the risk of CD pulling out a catheter after insertion, whilst significant, do not outweigh the benefits to CD of preserving his life - or at least providing a chance of his live being preserved - a life that brings him times of considerable pleasure. The presumption that it is in his best interests to preserve his life is not displaced by the evidence as to the burdens and risks that will come with attempts to preserve his life because those burdens are balanced by benefits from a life that can be preserved. Preservation of life may only be for a few months at most but at the end of a life, that period of time can be particularly precious. The evidence about CD is that in the present circumstances he would have wanted treatment to be given to try to preserve his life.

31. Accordingly, I do not accept that it would be contrary to CD's best interests to insert a new tunnelled catheter and to continue haemodialysis. As the parties invited me to do in the event of such a conclusion, I shall declare that it is in CD's best interests and lawful for him to have a new tunnelled haemodialysis catheter inserted under sedation or general anaesthetic and to receive haemodialysis thereafter subject to any significant change in his clinical presentation and provided that the treating clinicians are willing to offer this treatment. The applicant may use reasonable and proportionate force to administer sedation and/or general anaesthesia to the minimum extent necessary for the insertion of the tunnelled catheter. I shall authorise any deprivation of liberty occasioned by the use of such force.

32. I am grateful to counsel for their assistance. Although I have not made the order the Trust sought, the medical professionals including Dr A have given full respect to the difficult decision-making in relation to CD's care and treatment. EF and GH, who articulated their case and gave their evidence with great composure, expressed their sincere thanks to the staff and healthcare professionals at the Trust for the care they have given and continue to give to CD. Dr A spoke warmly of the family's dedication to CD. The family and the Trust have good relations which I hope will continue.