Neutral Citation Number: [2024] EWCOP 39 (T3)

Case No: 14258984

**COURT OF PROTECTION**

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 17/06/2024

**Before** :

**MS JUSTICE HENKE**

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**Between :**

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|---|---|
| **North Central London Integrated Care Board** | **Applicant** |
| **- and -** | |
| **(1) AA** | **Respondents** |
| **(by his Litigation Friend, the Official Solicitor)** | |
| **(2) MA** | |
| **(3) IA** | |

**Re: AA (Withdrawal of Life-Sustaining Treatment: No Best Interests Decision)**

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**Ms Victoria Butler-Cole KC** (instructed by **Hill Dickinson LLP**) for the **Applicant**
**Miss Katie Gollop KC** (instructed by the **Official Solicitor**) for the **First Respondent**
**Ms Kate Mather** (instructed under the **Direct Access Scheme**) for the **Second and Third Respondents**

Hearing dates: 10-13 June 2024

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# Approved Judgment

This judgment was handed down remotely at 2pm on 17 June 2024 by circulation to the parties or their representatives by e-mail. It is subsequently published in anonymised form at 2pm on 29 July 2024 by release to the parties and the National Archives.

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**Ms Justice Henke :**

## Introduction

1. At the heart of this case is AA. AA is 33 years old. He is presently being cared for at the Regional Hyper-Acute Rehabilitation Unit (RHRU) at Northwick Park Hospital. There, he receives life-sustaining clinically assisted nutrition and hydration. The Applicant is the ICB responsible for commissioning his placement there. The relevant NHS Trust and hospital are not parties before me. The Applicant did not make clinical decisions in relation to AA. All clinical decisions were made by the treating hospital. The First Respondent is AA himself. He appears by his litigation friend, the Official Solicitor. His parents were joined as Second and Third Respondents by me on 29 May 2024.

## Factual Background

2. AA was diagnosed with diabetes at a young age. Sadly, he developed chronic renal failure which was treated with dialysis. On 5 December 2023, AA underwent a kidney and pancreas transplant at a hospital in Oxford. There were surgical complications, and he developed a pseudoaneurysm. He was thought to be recovering but five days later he suffered a major haemorrhage which led to a cardiac arrest. CPR was required for about 28 minutes before spontaneous circulation was achieved. As a consequence, AA suffered a significant hypoxic ischaemic injury. He was moved to the Regional Hyper-Acute Rehabilitation Unit at Northwich Park Hospital on 13 February 2024 for assessment.

3. Between 14 February and 24 April 2024, AA has undergone several WHIM and CRS-R assessments and on 4 April a further MRI brain scan. His treating clinician, Professor Turner-Stokes, considers that these tests have not shown any trajectory towards improvement. AA's parents have engaged in best interests discussions with the clinical staff. There have been several meetings, the first of which took place on 22 February. At the first meeting, AA's prognosis and ongoing treatment was considered. His parents were told that "*the MRI and EEG changes allow us to say that sadly, AA is highly unlikely to make a recovery. There is not enough brain tissue left to allow the brain to recover. There is not enough brain left to allow new connections to be made and so in AA's case, sadly, the brain is not 'neuroplastic'*". It was explained that all ward-based treatments would be offered but that the clinicians would no longer offer escalation to ITU, ventilation or CPR as a result of the severity of his brain injury. In subsequent best interests meetings, including on 15 March 2024, it was evident that AA's parents did not agree with the treatment being provided nor the accuracy of the prognosis. They considered that life-sustaining treatment should continue and that it was too early to decide to withdraw this. They considered that AA would want treatment to continue and raised concerns that the medical team "should be trying to prolong life, not end it". During the best interests meeting on 26 April 2024, Prof. Turner-Stokes highlighted that the treating team had reported increased evidence of pain behaviours (grimacing etc) since some of the medications were stopped a few days before. She explained that the team would restart the Gabapentin, and also a hyoscine patch to try to reduce his drooling. His parents were reluctant to go down a palliative care route, but the treating team were of the view that it may be necessary if there is still concern about underlying pain, having tried all the simpler

approaches. On 30 April it was reported at the MDT meeting that AA was displaying fewer grimacing behaviours and his drooling had decreased as a result of Gabapentin and hyoscine. There was no need to progress to palliative care or further pain medication at that time.

4. At the best interests meeting on 10 May, the view of his treating clinicians was that it was in AA's best interests to be discharged from hospital and transferred to a nursing home where he would continue to receive nursing-home based palliative care, including CANH, and oversight from the Royal Free Hospital renal team. The palliative care plan dated 17 May which was filed alongside the application was formulated specifically to provide a 'plan for medical and palliative care if AA were to be discharged to a specialist nursing home.'

5. On 13 May, AA's tracheostomy was changed from a cuff tracheostomy to cuffless. He is not ventilated, but by the time of the hearing on 10 June he was receiving oxygen through his tracheostomy. He receives nutrition, hydration, and medication via a PEG feed.

6. On 14 May Professor Wade (second opinion doctor) visited AA and thereafter produced a report. He considered that:

   > "*[AA] is minimally responsive and has no awareness of himself; he shows increasing pain behaviours and may have some evanescent experience of pain. I concluded he would never improve from his current situation. I considered it was against his best interests to withhold palliative care even though his parents do not accept this. I felt it should be started as soon as possible. I concluded it was against his best interests to continue with clinically assisted nutrition and hydration, but the Court of Protection must make this decision*."

7. The last best interests meeting took place on 22 May 2024, at which time the parents were informed of the treating clinicians' intention to issue proceedings in the Court of Protection. AA's parents were told that following Prof. Wade's report the clinical team considered that it was no longer in AA 's best interests to continue life sustaining treatment because 'optimal end of life care cannot be guaranteed in a nursing home setting'. As such, the application was made in respect of withdrawing CANH. At the same meeting the treating team communicated their concern that increase in pain relief medication was needed. AA's parents continued to disagree with interim palliative care being commenced. As a consequence, the ICB made an urgent application to the court seeking authorisation to administer morphine and midazolam in accordance with the palliative care plan ahead of a final decision as to continuation of life sustaining treatment being made. The ICB considered it was imperative that AA receive morphine and midazolam, when clinically necessary, because he had exhibited behaviours which could be interpreted as indicating pain. AA' s mother and father expressed concern that this medication would accelerate his death and make him more drowsy and less aware than he otherwise would or could be. They were of the view that the clinicians are seeking AA 's death indirectly by administering palliative care pain relief.

8. AA has been diagnosed by Prof. Turner-Stokes as being in a very low-level prolonged disorder of consciousness on the border of a vegetative state/minimally conscious

state-minus. Given there has been no improvement in the past 6 months, it is her opinion that he is highly unlikely to ever regain consciousness. It is the consensus of the clinical team that AA should receive palliative care to minimise his pain and discomfort and that CANH should be discontinued. AA's parents object. They dispute the prognosis and the diagnosis. They oppose palliative care and withdrawal of CANH. They think he can improve.

## Procedural Background

9. In that context, on 24 May 2024 the Applicant made an application for personal welfare orders under the Mental Capacity Act 2005. The court issued the application on 28 May 2024, and it was served on AA's parents the same day. The next day the case was listed before me in the Urgent Applications list. At the time the case came before me the Applicant, on the advice of the treating clinicians, argued that there were in reality only two available options for AA's continued treatment. They were:

    i. Option 1 - Transfer to one of two identified nursing homes on a palliative care pathway, with no readmission to hospital, and continuation of clinically indicated medications and CANH.

    ii. Option 2- Withdrawal of CANH at Northwick Park Hospital, with provision of palliative care.

10. At the hearing before me on 29 May 2024, the Applicant was represented by Ms Butler-Cole KC and AA through his litigation friend the Official Solicitor by Miss Gollop KC. The parents attended but were not represented. However, I was told that their legal representative had said she would be able to consider the papers in the next two days. I therefore gave standard directions. In addition, I directed that any application for expert evidence was to be filed and served by 6 June 2024. I listed the case for a further remote hearing on 10 June 2024 with a time estimate of an hour.

11. In the interim I declared that I was satisfied that there is reason to believe, for the purposes of section 48 of the Mental Capacity Act 2005, that AA lacks capacity to:

    i. conduct these proceedings; and

    ii. make decisions about his medical treatment, in particular the provision of CANH, pain relief and palliative care.

12. At the hearing on 29 May, the clinical evidence before me was that AA was likely to be suffering pain and that the pain relief to be administered to him (including morphine and midazolam) would not have the effect of shortening AA's life. His parents did not agree. They contended that AA was suffering no more pain than he had before the transplant operation and that his pain could be managed conservatively by regular paracetamol. I therefore made an interim best interest decision. I accepted the clinical evidence and decided that it was AA's best interests that his pain should be managed effectively until the court was able to make a decision about which of the two treating options then before the court were in AA's best interests. Accordingly, I authorised pain relief to be provided to AA in accordance with the advice of his treating clinicians.

13. On 5 June 2024, the Official Solicitor made an application for the court's permission to instruct a consultant neuro-rehabilitation expert to review AA's medical records, speak with his treating team and family members, visit AA, carry out assessments as she deemed necessary and provide an expert opinion on condition, prognosis and best interests. That application was opposed on behalf of the Applicant.

14. This case returned to court on 10 June 2024. Again, it was before me in the Urgent Applications List. It had been given a time estimate of an hour. That was an appropriate time estimate given the issues that the court anticipated having to determine were limited to:

    i. Directions leading to a final hearing including the disclosure of medical records;

    ii. Review of the interim decision in relation to pain relief; and

    iii. A determination of any application for expert evidence.

15. However, the hearing on 10 June 2024 did not proceed as anticipated. Firstly, AA's parents were not represented; there had been an issue with funding. Secondly, from around 5 June 2024, there was information that AA's clinical condition was deteriorating. That deterioration was confirmed in the Applicant's position statement for the hearing on 10 June 2024. When the application first came before me the clinicians considered AA's life was likely to be measured in weeks, possibly months. By 10 June 2024 the position was that the clinicians considered he had at best weeks to live and possibly days. The deterioration was not linked to the pain relief he was receiving rather it was the expected trajectory in his condition which was effectively 14 days further on than at the date of application. As a consequence of the changing landscape of the case, I adjourned the application until later the same day to enable all parties to consider their positions.

16. In response to AA's deteriorating condition and in anticipation of the hearing on 10 June, Prof. Turner Stokes contacted the two nursing homes identified in Option 1 to check whether they were still able to receive AA. Both declined to take him. They did so in view of the fact that AA had already progressed to the end-of-life phase, there was a risk of AA dying in transit, AA's need for IV medication, and the need for his end-of-life palliative care to be monitored and implemented at consultant-level and having regard to the continued objections of AA's parents to the provision of palliative care.

17. Consequently, at the hearings on 10 June 2024, the Applicant's position was that there was only one possible option for AA's treatment, namely the end-of-life palliative care plan dated 9 June 2024 which they sought to file. Given that the Applicant's case was now that there was only one available option, this court asked the Applicant to set out the relief it now sought. That request resulted in a document entitled Application for an Order Under the Inherent Jurisdiction of the High Court in which the Applicant sought relief not within the Court of Protection but pursuant to the Inherent Jurisdiction of the court. The relief sought was "*a declaration that it is lawful for the treating hospital to implement the palliative plan dated 10 June 2024 in respect of AA*". It was argued that the declaration sought ought to be granted because:

i. There is no basis to suggest that the proposed PCP is in breach of the duties owed to AA in negligence.

ii. There is no basis to suggest that the proposed PCP is in beach of AA's rights under the European Convention on Human Rights. The courts have long held that granting declarations as to the withdrawal or withholding of life-sustaining treatments does not violate the patient's rights under Art 2 or 3 - *NHS Trust A v MRS M and NHS Trust B v Mrs H* [2001] 2 WLR 942 and *Burke v GMC* [2004] EWHC 1879 (Admin).

iii. There is no necessity for further medical evidence in light of the opinions already received, there is no evidence gap and the parental objections to the plan being that AA will recover and that his current presentation is a consequence of the medical treatment he is receiving, not his underlying and deteriorating medical condition.

18. The case was re-listed before me sitting in the Urgent Application court at risk during the afternoon of 12 June 2024. It had been listed in the afternoon at the request of Counsel for the parents who had been instructed late on 11 June and Counsel for the Official Solicitor. In the legal submissions prepared on behalf of the Applicant for the 12 June 2024 hearing, the primary position of the Applicant was that "*a final decision must be made at this hearing as to the implementation of the end-of-life palliative care plan for AA*". The Applicant continued to propose that the court makes a declaration pursuant to the inherent jurisdiction of the High Court without requiring a separate set of proceedings, but that said: "*the Applicant would endorse any route that enables a final decision to be made promptly in AA's interests*". Very properly, Counsel for the Applicant then set out the routes that she said the court could take and the arguments in respect of each:

i. The court could make a decision pursuant to s.16/17 MCA 2005 to implement the end-of-life palliative care plan before the court. The treating clinicians are unwilling to continue to provide CANH and oxygen to AA while treating him with minimal levels of pain relief, as is happening at present. That contradicts RCP guidelines on palliative care following withdrawal of active treatment for patients in prolonged disorders of consciousness and is contrary to their clinical judgment. In that context I was taken to Moylan J's judgment in *An NHS Trust v L and others* [2012] EWHC 4313 (Fam) and paragraphs 112-117 thereof. Given an urgent decision is required, this court could take the best interests route, notwithstanding the lack of evidence of any available option. If the court were to take that route, then the order sought would be a declaration pursuant to s.15 that AA lacks capacity to make decisions about his medical treatment, and the provision of consent pursuant to s.16-17 MCA 2005 to the implementation of the end-of-life palliative care plan.

ii. Where, as here, there is only one available route, it is submitted on behalf of the Applicant that the appropriate way forward is to seek a declaration of lawfulness pursuant to the court's inherent jurisdiction without requiring a separate application to be made. In support of that argument, I was taken to *XCC v AA Anor* [2012] EWCOP 2183, *Barnet Enfield and Haringey Mental*

*Health NHS Trust & Anor v Mr K & Ors* [2023] EWCOP 35 at paragraphs 96-98 and *Nottinghamshire Healthcare NHS Trust v RC* [2014] EWCOP 1317. In the context of this argument, I have also read Baker LJ's judgment in *Re G (Court of Protection: Injunction)* [2022] EWCA Civ 1312. It is argued that the declaration sought in the circumstances of this case is not markedly different from brain stem death cases where the court reviews all the medical evidence , only grants permission for additional expert evidence if there is reason to consider that the treating doctors have gone wrong or have failed to follow the relevant guidance.

iii. Another route would be to require the Applicant to issue a Part 8 application. It is argued that would be inappropriate here because there are disputes of fact.

iv. Lastly, the court could simply make no order in relation to AA's treatment. That route is said on behalf of the Applicant to be inappropriate because of AA's parents' strong objections and because an order if made will support the implementation of the palliative care plan.

19. The Official Solicitor responded to the Applicant's change of case by an email, copied into all parties, on 11 June 2024 in which she sought clarification from the Applicant about what it was not applying for. The Applicant confirmed in response that it was *not* seeking any of the following:

    i. An order to amend or withdraw the application made to the Court of Protection;

    ii. The court's consent to withdrawal or withholding of artificial nutrition;

    iii. The court's consent to withdrawal or withholding of hydration;

    iv. The court's consent to administration to AA of any medication or its consent to provision to him of any other intervention, investigation or treatment

20. In a further email on 11 June, the Official Solicitor asked the Applicant what treatment it proposed to commission in the event that the declaratory relief applied for on 10 June is not granted. The response was that if the court declines to make any declaration as to lawfulness, "*the ICB expects that the hospital will proceed to treat in accordance with the clinical judgment of the clinicians*".

21. Against that background, the Official Solicitor in her position statement for the hearing on 12 June 2024, reminded the court of the old maxim *more haste, less speed.* Notwithstanding the Applicant's assertion that there is no alternative, the Official Solicitor would like, but has not had time, to take the following steps:

    i. Meet AA's parents and brother in person to obtain a full picture of AA and gather evidence of wishes and feelings;

    ii. Visit AA;

    iii. Instruct an expert in palliative care to consider the treating clinicians' PCP;

iv. Instruct an expert in rehabilitative medicine, provided with AA's medical records (which the Official Solicitor does not have), to provide an independent view on pain experience, condition and prognosis including life expectancy, and to consider whether care at home is practical;

v. Seek some evidence from the ICB about what searches it has made for a healthcare facility that could and would admit AA, whether it has considered commissioning weekend consultant cover for AA, and whether it has considered care at home.

22. The Official Solicitor was concerned that AA was becoming marginalised. His voice was not being heard. AA's parents had just secured legal representation and had not had the opportunity to prepare their case. There was a perception of unfairness. The Applicant had had time to prepare whereas AA's parents had not. The Official Solicitor was concerned that the approach urged upon the court by the Applicant could become an alternative to the Human Rights Act 1998-compliant best interests approach to judicial determination of disputes about withdrawal of life-sustaining care from adults who lack capacity endorsed by the Supreme Court in *Re Y* [2018] UKSC 46. In her view the contrast between the P-centred *Re Y* procedure, and the Applicant's healthcare-provider-centred, "no alternative, lawfulness only IJ procedure" is stark.

23. On behalf of the Official Solicitor, it was argued that whilst the High Court may have power to exercise the inherent jurisdiction and the discretionary power to grant the relief sought, the issue was whether the Court should permit the Applicant to access that jurisdiction and whether the relief sought should be granted. The question was posited - what should the legal test be if proceedings are to be transferred from the Court of Protection to the Inherent Jurisdiction. On behalf of the Official Solicitor the argument was advanced that it should be a best interests decision. It is common practice that an application under COP r.13(2) to withdraw an application before the Court of Protection is a best interests decision. A best interests test would be the most appropriate because transferring to the Inherent Jurisdiction would terminate the Court of Protection proceedings in which the best interests test would apply.

24. In the Position Statement prepared on behalf of the Official Solicitor for the hearing on 12 June 2024 it was argued that: -

i. The assertion that there is no alternative option is predicated on the assumption that the Applicant's evidence about AA's pain experience is reliable. Both the reliability of the data said to be proof of pain and its interpretation are disputed by AA's parents. This court cannot assume that the doctors must be right.

ii. Where the facts are in dispute, the burden of proof is on the party contending for the factual finding. If the court were not persuaded that the ICB had proved to the civil standard that AA is experiencing pain, or the degree and frequency of pain asserted, provision to him of medication that put him into a coma might not be lawful. If AA's treating team at Northwick Park nevertheless

insisted on providing him with that treatment, arguably the ICB would have a duty to commission care from a different treating team.

iii. Even if there is no alternative, where parents are strongly opposed to the treatment the state wishes to provide to a person in a minimally conscious state, fairness (and Art 6 is engaged) may require a best interests determination. That was the approach of Judd J in *London North West University Healthcare NHS v M and Others* [2022] EWCOP 13.

iv. As to the assertion that there is no alternative to the PCP, the Official Solicitor suggests that the court should not assume that is the case. It seems that applying *R (Ferreira) v HM Senior Coroner for Inner South London and Others* [2017] EWCA Civ 31, AA is not in state detention and is free to leave. There is no information that informs the issue of whether AA would choose to leave hospital, take his chances with pain, and have a very short, life without a tracheostomy at home, in preference to remaining in hospital and being put into a coma.

v. The proposed declaratory route is not Human Rights Act compliant. The Official Solicitor is not clear that she understands what is meant by "lawfulness" in relation to the provision to AA of medical treatment when that concept is divorced from best interests. She is unclear about how he can be lawfully administered coma-inducing drugs in circumstances where:

    a. There is no consent for that intervention;

    b. There is a dispute about whether AA is experiencing pain;

    c. AA's parents are strongly of the view that the PCP is not what he would have chosen for himself and not in his best interests.

vi. The Official Solicitor is also unclear about how CANH can lawfully be withheld absent a determination by the court that it is in AA's best interests for that treatment to stop. Again, she notes that AA's parents are likely to be strongly of the view that AA would want to be provided with all life-sustaining treatment.

vii. If the Applicant's submission is that the PCP should be declared lawful because it represents care of a reasonable standard, is non-negligent, meets the *Bolam* test, is gold standard, or is in accordance with national guidelines, she disagrees. She submits that in this context, lawfulness cannot be divorced from best interests. Treatment should be tailored to the individual. No assumption should be made that every PDOC patient will want gold standard pain relief at end of life: some might choose bronze standard pain relief and accept some distress if that option is less restrictive than a coma.

viii. If the Applicant considers, as it appears to, that the treating team and Trust can provide AA with care according to the PCP lawfully and without incurring liability because s5 MCA will apply to their actions, then the exercise of the

inherent jurisdiction is unnecessary. She notes that s5 is concerned with best interests.

25. In the Position Statement for 12 June the submission on behalf of the Official Solicitor was that this this court, which is seized of MCA proceedings, that should decide what is in AA's best interests, not his doctors.

26. AA's parents supported the Official Solicitor's position. The proceedings have been rushed. They have been unfair. They have not had time to marshal the evidence upon which they would wish to rely or their arguments. Their primary position is that:

    i. They seek AA's transfer to a different hospital;

    ii. They seek further expert opinion from a neurologist and potentially from a nephrologist and an expert in rehabilitative medicine;

    iii. They wish him seen by an ENT specialist in relation to his tracheostomy;

    iv. The current pain medication is neither necessary nor in AA's best interests. It is having deleterious effects. They wish it to stop. They do not accept he is experiencing any more pain than before his surgery;

    v. They wish to challenge the clinical evidence before this court;

    vi. There are other treatment options not just the PCP proposed by the Applicant.

**The Hearing on 13 June 2024**

27. The proposed hearing on 12 June was ineffective. The case was not reached until too late in the afternoon. I therefore adjourned the case until the next day and transferred as much of my list that day as possible to another judge.

28. By 13 June 2024, the application had generated a main bundle of 469 pages, a supplemental bundle of 41 pages and an authorities bundle of about 340 pages. In addition to reading all the documents provided to me. I heard evidence from Prof. Turner-Stokes, a Consultant in Rehabilitation Medicine at the Northwick Park Hospital and brief evidence from AA's mother.

29. Professor Turner-Stokes gave evidence in person. She confirmed the truth of her four statements and produced a chart which documented AA's pain reactions. The manner in which Professor Turner-Stokes gave her evidence demonstrated she understood the gravity of the clinical judgments that she had to make in this case. These were difficult decisions for anyone to make but she had made them. For her and the clinical treating team, the declaration the Applicant sought would be "*helpful*" but if the court did not grant it, if it remained clinically the right thing to do, they would do it anyway. If the PCP was implemented, death may come quickly. He has multiple conditions, and she could not say which condition would precipitate death or exactly how long it would be before death occurred. In a person without his multiple conditions, death would be anticipated in 2-3 weeks although 9 days would be the average. Given his multiple conditions, if the PCP were initiated death could be within 24-48 hours. If he

is maintained on his low doses of pain relief, his life may be measured in weeks, but it could be days – "*He is balanced on a knife edge*". Later in her evidence, she stated "*I can't tell you how close a knife edge this is*". In relation to pain, there is evidence of increasing pain reactions. Boluses of his current medication could not be used to augment his current pain relief. That would be clinically contraindicated. She would not be prepared to give it even if the court considered it to be in AA's best interests. AA's condition has now reached the point where there is a need to move to the next stage of the PCP and give low dose phenobarbitone. That would be the safest and clinically appropriate option. It is Stage 2 of the PCP. It is not compatible clinically with continuing CANH and oxygen. The Professor had considered a nursing home to accommodate parental opposition to coma and a withdrawal of CANH but when it became clear the nursing homes would not take him, her position changed. She intended to follow the PDOC Guidelines; considering that to do so was in the best interests of her patient, AA. In that context, when asked questions about adapting the plan to suit AA, her response in summary was that she would follow the Guidelines but adapt the PCP to meet his clinical symptoms as they occurred.

30. AA's mother gave evidence remotely. She was calm and dignified. She confirmed her written evidence before the court. She and her husband are experienced medics. She a health visitor and he a retired surgeon. They do not accept that AA will not recover. They do not accept that his pain scores are any greater than before the operation. Miss Gollop KC asked her sensitively in cross-examination – if AA is in pain and knew he could not recover from his current state, what would AA want? Her response was clear and firm. AA had had diabetes since he was 8 years old. He had experienced ill health, pain, and medical procedures. In that context, he had had tattoos inked on his body of "*Hope never dies*" and "*Love the life you live, live the life you love*". He, like his parents, is a committed Christian. He would choose to live and have a natural death.

## The Parties' Positions in Closing

31. The Applicant's position remained as set out in writing. The Applicant asked the court to grant a declaration of lawfulness under the Inherent Jurisdiction or a declaration of lawfulness and best interests under the MCA, on the evidence available. It was submitted on behalf of the Applicant that there is only one available clinical option. The PCP cannot be tinkered with. Professor Turner-Stokes had spoken with colleagues, and they would not move to stage 2 pain relief unless the CANH and oxygen was stopped. The Applicants are not slavishly adhering to the PDOC Guidelines. There is no need for any further expert evidence. There will be only one available clinical option unless the court appointed an expert who identifies an alternative and is willing to take over and implement any amended care plan. AA has a higher level of awareness. He is capable of experiencing pain and it is observable. It is why the pain relief is important and Stage 2 is now indicated. No doctor is willing to implement any other plan. Even when factoring in AA's values and beliefs at their highest for the purpose of a best interests decision, the balance will come down in favour of the plan. Ms Butler-Cole KC underscored in closing that there is no other clinical option available, and a decision needs to be taken now.

32. On behalf of the parents, I was informed in closing that his mother who sleeps at his bed side had instructed her that AA was stable and comfortable last night. AA is a

vibrant young man who wanted to succeed. He would want to make the most of his life and not want it foreshortened. His wishes and feelings have not been taken into account by the Applicant. They have witnessed him in pain before and after the operation. They see no change. He appears to them to be in pain no more than before the operation and they are best placed to judge. They continue to seek expert assessment in this court.

33. Miss Gollop KC on behalf of the Official Solicitor informed the court that the Official Solicitor felt uncomfortable and railroaded by the Applicant's position before the court, which she set out bluntly. There were no circumstances under which the Applicant would provide any treatment other than that prescribed in the PCP. Under no circumstances would the Applicant deviate from the Guidelines. No further evidence from a court appointed expert would change their minds. The expert would have to be prepared to implement any alternative plan as they would not. The Applicant would be more comfortable proceeding with the benefit of a court order but if they did not get one, they would proceed in accordance with their clinical judgment and implement the PCP. The role of the Official Solicitor in this case had been rendered impotent. She had considered returning the invitation to act because there was nothing that she could do that would make a difference. AA was too fragile to leave the hospital. The clinical team had settled on a plan from which they would not deviate no matter what. The declaration sought by the Applicant is for the benefit of the staff not for AA. It is not human rights-compliant and, if they are going to do it anyway regardless of the court's case management or judgment, what is the point? AA and his family have been side-lined and marginalised. AA is a man who has experienced pain and ill health before. He has lived with a life-limiting condition since he was 8 years old. His views about treatment and how he would want to live and how he would want to die will have bene informed by his past experiences. His parents know him well. AA's and his family's wishes and feeling values and judgments will need to be factored into any best interests decision. If asked he might prefer the bronze service and a longer life rather than the gold standard calm coma and a quick death. It is argued by the Applicant that this court does not need to make a best interests decision but only decide whether the intended plan is lawful. I am asked rhetorically, should I do that when the court knows that further information is available from his siblings and potentially from an expert who could see AA in short order. The court does not have evidence about whether AA would want a longer life with treatment outside the Guidelines or a shorter life within it.

## My Consideration and My Conclusion

34. This is a truly tragic case. I accept the clinical evidence that AA's brain stem is damaged. That has led to a failure to be able to control many essential functions including coordinated bowel function, swallowing, and breathing. His brain injury is not survivable. All the evidence before me is that he will not recover. He has a state of awareness. He opens his eyes when his mother calls his name. He is likely to be able to experience pain and the evidence, which I accept, is that he is experiencing more pain recently. The current pain medication which I authorised on 29 May has not caused his deterioration. On the current pain relief, which is at low dose, he continues to show a pain reaction.

35. I have earlier in this judgment briefly summarised the best interest meetings that quite properly took place once AA moved to the RHRU. Given the diagnosis and prognosis, the trajectory of AA's condition was and is inevitable. AA's parents fundamentally do not accept and have not accepted the clinicians' opinion throughout his admission to hospital. Their stance has been clear for a long time. In my view, the court should have been accessed sooner than it was. I consider that leaving the application until late May 2024 has had two significant consequences: -

    i. There is now only one available option before the court, and

    ii. There is a perception of unfairness. The Applicant has had the time and resources to marshal its evidence and its arguments before applying to this court. AA's parents, against a background of profound distress, have had to respond at pace. They and the Official Solicitor have had to seek out experts who would and could report in this case. That has not been an easy task. Then when the Official Solicitor did on 13 June 2024 find an appropriate expert who could give this court an overview of AA and the treatment proposed for him within a short time frame which would not disrupt the plan to implement the PCP, the response from the Applicant was that (a) the evidence was unnecessary as there was no evidential gap in the case and (b) unless the expert was prepared to take clinical responsibility for AA and implement any alternative plan, it was futile. The clinical opinion would not change, and the clinicians would continue in accordance with their clinical opinion with the PCP.

36. The proceedings before me are brought under the MCA 2005. It is rightly accepted on the overwhelming evidence before me that AA lacks capacity.

37. I have reminded myself of s.1(5) MCA and s.4. If the court is being asked to exercise its powers under the Act, then the court is required to exercise its judgment and to determine the application in accordance with the Act by reference to all the relevant circumstances. However, in this case I find myself with no choice of available treatment options. As Moylan J put it in *An NHS Trust v L &* Others [2012] EWHC 4313 (Fam) at paragraph 113.

    "*113 […] If there are no treatment options, then the court has no effective choice to make. This is not the same as the situation where the medical evidence is all to one effect as in the case of NHS Trust v MB and others [2006] EWHC 507 Fam.*"

38. I agree with the general observations of Moylan J in at paragraphs 113-116 in *An NHS Trust v L & Others* (above).

39. I accept the well-established principles that:

    i. a patient cannot require a doctor to give any particular form of treatment and nor can a court – *NHS Trust v Y* [2018] UKSC 46.

    ii. It is an abuse of process to try to use a best interests declaration under the MCA 2005 to persuade a clinician to provide treatment where none is being offered - *AVS v A NHS Foundation Trust & Anor* [2011] EWCA Civ 7.

40. Nevertheless, I am asked by the Applicant to consider proceeding to make a best interests decision as Moylan J did in *An NHS Trust v L & Others* and as Judd J did in *London North West University Healthcare NHS Trust v M* [2022] EWCOP 13. I am conscious that in *An NHS Trust v L & Others* Moylan J had heard extensive evidence over many days and that he reluctantly proceeded to make a best interests decision because all parties asked him to and no one took the no other available option point before him. In the *London North West* case Judd J had had the opportunity to receive and hear evidence from the treating clinician, the second opinion doctor and another who appears to be a court appointed expert who had provided a review. Having read that case with care, it seems to me that the case Judd J had before her was one where all the available evidence, including that obtained through the court process, was all to one effect. The case before me is very different. I do not have the benefit of an expert overview as envisaged by the Official Solicitor. That application was not pursued. I understand why. It would be futile to do so given the Applicant's clear position that regardless of any further expert opinion, they were only prepared to implement the PCP they had submitted to this court. The case before me is built on the evidence provided by the clinicians and that obtained by them. I do not for one moment doubt the good intentions or integrity of the clinicians in this case. Professor Turner-Stokes in evidence was an obviously committed and caring professional who understood the gravity of her task and made her clinical judgment in accordance with her considerable expertise and conscience. The clinical view is that there is only one option, and the clinicians will only treat AA in accordance with that option. This case is stark. There is only one available option before this court. The reality is that this court has no choice to make. Accordingly, I have concluded that there is no best interest decision to make here, and I do not do so.

41. That is not the end of the matter because the Applicant's preferred route is that I should make a declaration in the inherent jurisdiction. It is common ground between the parties that a Part 8 claim would be inappropriate given the substantial factual disputes in this case. Thus, I am asked by the Applicant to make a declaration without requiring a separate application. I accept on the basis of the authorities cited to me by Ms Butler-Cole KC on behalf of the Applicant that that jurisdiction exists under s.47 MCA 2005. I further accept that it is not suggested in this case that the clinicians are acting negligently and there is no suggestion that the PCP is in breach of AA's rights under the European Convention on Human Rights – see *NHS Trust A v Mrs M* (above). The issue for me is whether in the circumstances of this case it is necessary to make the declaration sought. Clinicians are not legally obliged to seek a declaration from a court as to the lawfulness of any proposed treatment – see *Re Y* [2018] UKSC 46 at paragraphs 29-33. Professor Turner-Stokes gave evidence that regardless of whether or not I granted the declaration, the clinicians would continue to treat AA in accordance with their clinical judgment and implement the PCP. That begs the question: why is the declaration being sought when whether or not I grant it does not affect the outcome for AA? It appears to me that the declaration is really being sought to protect the clinicians and medical staff now and in the future from potential legal action given AA's parents fundamental disagreement with the PCP. I have considered whether I should grant the declaration sought in such circumstances. If I thought that on the ground that the declaration would make any difference to the outcome for AA then I may have been persuaded to make it. But the reality here is that the declaration will not alter anything. The clinicians will continue to treat in

accordance with their clinical judgment whether or not I make the declaration. AA's parents' views, whether reasonable or not, are deeply held. In my view, granting the declaration sought will not change his parents' views nor actually how they are likely to behave to staff implementing the plan. It is purposeless.

42. I understand the Official Solicitor's frustration in this case. I share it. The court process has been rendered nugatory. My preference would have been to permit the Official Solicitor's application to instruct an expert to overview the clinical evidence and that obtained from other sources by the clinicians. That could have been achieved in short order. It would have enabled the exploration of other treatment options or at least variations of the current PCP which might have been more in line with AA's wishes and feelings. Had it occurred the court would have had arms-length evidence which may or may not have supported the views of those treating AA. However, I understand why it was not pursued. Given the stance of the Applicants it would have been futile to do so unless the expert was prepared to take clinical responsibility to implement any alternative plan. The stark reality of his case is that AA is too fragile to be moved to another hospital and that those at the RHRU are clear that the only treatment plan clinically viable for AA and which they are prepared to implement is the PCP. The court has no choice and I have asked myself whether in circumstances such as these, when the court has no choice at all, it should rubber stamp the decision of others. I have decided that I should not. In coming to that decision, I should emphasize that I have the greatest respect for the clinicians in this case and the difficult decisions that they have had to take and will have to take until AAs death. They do so in accordance with their hypocritic oath and to the highest of professional standards. I do not criticise them or the judgment they have made. However, the reality of this case is that the treatment decision in this case is purely a clinical decision not the court's decision. The court's approval is not required to implement it. The court is not needed to sanction the plan and the court has no further role to play in what treatment AA does or does not receive.

43. I have reminded myself of the overriding objective and in particular the factors in COP r.1.1(3). Given that there are simply no available alternative options to that proposed by the Applicant, there is sadly nothing left to do. There is no further step I can take or ought to take to ensure AA's interests and position are properly considered and the case is dealt with fairly. There is no direction or order I make, interim or final, which is going to affect the course of events. These proceedings are now a purposeless distraction from AA and the remainder of his life however long it may be.

44. Therefore, on the facts of this case and for the reasons I have given I have decided to make the declaration of incapacity as sought; to decline to make the declaration sought under the Inherent Jurisdiction and to dismiss the application for a personal welfare order brought by the Applicant. The transparency order I made on 13 June 2024 is extended in duration until 6 weeks after the date of AA's death or further order whichever is the sooner.

45. As I have been writing this judgment, I have had in mind Ms Gollop KC's submission that AA has been marginalised in this case. I have not forgotten him. I accept the submission that AA has lived with a life limiting condition since he was 8 years old. He has experienced pain and suffering before. He chose, when he was able to do so, to live life to the full. He is an accomplished musician with videos uploaded to Youtube.

He lived his life in hope and his tattoos reflect his philosophy of life. I have accepted the clinical evidence that there is no prospect of recovery in this case. There is no direct evidence before me from him as to what he would have chosen if he knew that he was not going to recover and that he would experience pain. He may have chosen a longer life and tolerated pain over a shorter but pain free life. His mother thought he would choose life. His siblings' views have not been ascertained.

46. When Professor Turner-Stokes was asked about a bespoke plan for AA, she told me that the PCP plan for AA would be bespoke in that it would be varied to meet his presenting clinical symptoms as and when they occurred. That is a reasonable reaction from a doctor and is a reasonable clinical view, but it is one which in my judgment does not take into account that a person is more than their clinical symptoms. The plan, however, is set. The stance of the Applicant was clear in closing. Further evidence of AA's wishes and feelings is not necessary and, in any event, would not cause them to change their mind. I remind myself that would be an abuse of process for me to try to change the clinical view in this case. I therefore do not do so. I simply note that the PCP is the only option before the court and that further evidence from family about AA's wishes and feeling will not alter it.

47. As the modern saying goes, we are where we are. The clinicians will implement a plan which they consider to be in AA's best interests. I send AA and his family my best wishes. I know his parents do not accept the plan and consider he will recover. They are unlikely to be able to accept the clinical view that recovery will not happen. However, I hope that they are able to set aside their disagreements with the Applicants and desist from conflict with the staff at the RHRU. However much longer AA 's life may be, I hope that he and his parents are able to spend their time sharing their mutual love for one another without the distraction of any more conflict either on the ground or within court proceedings.

48. That is my judgment. I will deal with any short matters that may arise from it on the papers and in writing. It will not be published until the expiry of the transparency order.

## Postscript

49. I was notified of AA's death shortly after this judgment was circulated to the parties. I have already extended my condolences to his family privately. I now do so publicly.

50. After circulation, I received requests for clarification etc. I accepted some requests and rejected others. This version of the judgment is the outcome.