



Neutral Citation Number: [2023] EWCOP 38

Case No: 14000297

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 18/08/2023

Before:

THE HONOURABLE MR JUSTICE HAYDEN

Between:

**NOTTINGHAM UNIVERSITY HOSPITALS NHS
TRUST**

Applicant

- and -

(1) JM
(By his litigation friend, the Official Solicitor)
(2) NOTTINGHAM CITY COUNCIL

Respondents

Mr Rhys Hadden (instructed by Browne Jacobson) **for the Applicant**
Ms Sophia Roper KC (instructed by the Official Solicitor) **for the First Respondent**
Ms Lindsay Johnson (instructed by the Local Authority) **for the Second Respondent**

Hearing dates: 15th August 2023

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

THE HONOURABLE MR JUSTICE HAYDEN

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

MR JUSTICE HAYDEN:

Introduction

1. This is an application concerning serious medical treatment made on behalf of Nottingham University Hospitals NHS Trust (“the Trust”) who is responsible for the Nottingham Renal Unit at City Hospital, Nottingham. Proceedings were first commenced on 6th October 2022. The case comes before me today on an urgent application in the vacation list.
2. The proceedings concern J, a 26-year-old man. Though he was diagnosed with autism at the age of 5, he received very little support for it. JM’s mother (AM) has mental health issues too, having been diagnosed with schizophrenia. I do not think it is necessary to burden this judgment with JM’s childhood experiences other than to say it was characterised by trauma. The combination of trauma, which JM has been unable to address, and autism, confounds his efforts to process his experiences in life and thwarts reasoned decision-taking. In relation to the issues before this Court, which I will set out below, there is a consensus that JM lacks capacity. A psychological report prepared by Dr Steven Carnaby, Consultant Clinical Psychologist, dated 30th April 2023, provides a helpful insight into JM’s functioning.

“7. The social care records relating to [J] convey his childhood as one characterised by significant trauma...

10. I note that opinions about the appropriateness of [J]’s autism diagnosis have varied from aspects of his presentation seen as ‘consistent with mild ASD’ (914) to the diagnosis being doubted by school (528) or not known about at the time of a LAC Review (1679) but ultimately confirmed at other times (e.g. 1953).

11. There are references to specific responses from [J]’s or observations of his behaviour by others that in my view can be considered as consistent with a diagnosis of autism. These include the use of ‘unusual’ language or phrases... concrete language and literal thinking, difficulties with emotional regulation and sometimes fixating on one issue and ‘needing to exhaust this before he is able to move on to something else’ At other points, he is described as able to talk about how to cook and prepare meals to engage in work experience and give the impression of being a ‘very capable young man’.

12. While these various descriptions might appear to be ‘at odds’ with each other, it is also possible that they represent the ‘spikey’ profile of apparent levels of independence observed alongside areas where support is needed which can often be experienced by autistic people and observed by those supporting them. The CAMHS Consultation report dated 26.2.14 captures this phenomenon to some extent, in referring to both [JM] having ‘lots of good independence skills,

although he is felt to still be very vulnerable and innocent in many ways’.

13. In my opinion, [JM]’s ‘spikey’ autistic profile needs to be understood in combination with his traumatic experiences. Autism and trauma can overlap in terms of what the individual experiences and what others might observe, and there can be the risk of diagnostic overshadowing i.e the individual’s presentation being considered only in terms of autism without considering the impact of trauma. [JM]’s situation could be thought about in terms of autism being the ‘lens’ through which he experienced and made sense of the traumatic events throughout his life, affecting his ability to process what has happened to him at the time as well as having a longer-lasting impact in terms of shaping his identity and sense of self.”

Dr Carnaby considered that the extent and nature of JM’s trauma had “exacerbated the situation” and that JM struggled to process his experience through “his autistic lens”. Dr C, who gave evidence before me, very much agreed with Dr Carnaby’s analysis and was able to provide me with a number of examples which reinforced his conclusions.

3. JM was diagnosed with chronic kidney disease in January 2021 and has acquired Thrombotic Thrombocytopenic Purpura (“TTP”). He requires regular at least 4 hourly sessions of haemodialysis for a minimum of three times per week. It requires to be stated that the clinical consensus is that JM will die within 8-10 days, if he does not receive treatment.
4. The provision of dialysis for JM is facilitated via a “tunnelled” dialysis line, which is comprised of a tube which tunnels under the skin of JM’s upper chest and exits pointing downwards. Outside the chest, the line is seen to divide at a “Y”, revealing the two internal lumens, both of which end in separate connectors. JM does not accept a diagnosis of chronic kidney disease or his need for dialysis. His mother does not accept this either. Though they share the same view, which is irrational, Dr C is persuaded that they each independently hold the same view and JM’s belief structure has not been superimposed upon him. JM was compliant with treatment when in a hospital setting but frequently refused to attend appointments as an outpatient when living at his mother’s home. Repeated attempts to explain the need for dialysis and the potentially fatal consequence of not having it, have been unsuccessful, even with significant specialist psychologist support.
5. Following a series of capacity assessments, including by the independent expert, Dr Carnaby, to which I have already referred, on 19th June 2023, the court made declarations pursuant to s.15 of the Mental Capacity Act 2005 (“MCA 2005”) namely that JM “lacks capacity to: (i) conduct these proceedings; (ii) make decisions about the medical treatment he receives for chronic kidney failure; and (iii) to make decisions about whether to be accommodated in hospital or in a care home for the purpose of receiving treatment”. For completeness, in addition to the capacity assessments completed by the applicant, Dr Carnaby has completed 4 reports in total dated 6th January 2023, 6th March 2023, 30 April 2023 and 15th May 2023. Following the commencement of proceedings, there have been a number of agreed administrative orders. In recent months there have been remote hearings

before Mrs Justice Roberts on 19th, 29th June and 17th July 2023. Mrs Justice Roberts also conducted three “remote judicial visits” with JM on 20th, 27th and 28th June 2023.

6. Following JM’s refusal to comply with an interim move to A Nursing Home (or remain in hospital), the parties agreed and the court approved an “Escalation and Behaviour Support Plan” which declared that it was lawful not to compel treatment by chemical or physical restraint and to treat JM on a “responsive” basis only (i.e. by means of discussion, negotiation and persuasion without recourse to restraint). This declaration was made on 17th July 2023.

Urgent Application

7. The Trust has restored this matter to court on an urgent basis. On 11th August 2023 an ambulance was called to JM’s house. He was found in bed covered in blood from his dialysis line which had been significantly damaged after being cut close to the junction point. There is very little doubt that it was JM who cut the line. In consequence, the dialysis line had to be removed and subsequently JM has adamantly refused to have a replacement line inserted. The Trust convened a ‘best interests’ meeting, on 11th August 2023, which concluded that it would be in JM’s best interests to provide palliative care and cease to plan for further dialysis (discounting the insertion of a temporary or permanent dialysis line) unless this is positively agreed by him. For the avoidance of doubt, under this option the Trust would continue ‘gently’ to offer dialysis to JM and, if at any point he expressly agrees, a dialysis line would be inserted. This would include other active treatment. No attempt to insert a line, or otherwise, proactively treat him, would be made if JM’s health deteriorated to the point where he was unable to object or, indeed, if he becomes unconscious.
8. Ms Roper KC, on behalf of the Official Solicitor, rightly describes this as “*a desperately sad case... of a young man who is a victim of a particularly harsh fate*”. As Mr Hadden, on behalf of the Applicant Trust rightly and unambiguously states “*The stark and tragic consequence of this option is that, barring express acceptance by [J], he will inevitably die within a few days to a week*”. JM does not accept this. The doctors and nursing staff have made sensitive, creative and, if I may say so, very patient focused efforts to persuade JM to accept dialysis but they have not prevailed.
9. The Trust’s analysis of JM’s best interests is shared by Nottingham City Council and the Official Solicitor. The independent expert, Dr Carnaby, has also previously agreed that it would not be in JM’s best interests for any form of restraint to be used to compel his attendance at hospital or secure dialysis. JM’s mother and sister who have attended this remote hearing, are both very clear that coercive measures should not be used to compel JM’s treatment but that he should continue to be encouraged to accept a dialysis line and treatment. They also accept the implementation of a DNACPR while he continues to object. The current views of JM’s younger brother (D) were obtained following a telephone call. D said he did not think the hospital should compel a line but was not sure about DNACPR and wanted the clinical team to speak with his mum. JM’s mother and sister agreed with plan and DNACPR was restored. D made no further contribution.
10. JM’s mother has ongoing poor mental health and her support for her son’s dialysis has been variable. At various times in the past and during the course of her evidence to me, AM has expressed delusional beliefs regarding her son’s health. She told me that a witch put a spell on her son but she now believes that it is the dialysis that is making him unwell. I

incorporate this into the judgment only because it overlaps, to some degree, with JM's own thinking.

Factual background

11. JM was first diagnosed with chronic kidney disease in January 2021, and, following his non-attendance at outpatient clinics, he commenced an extended period of haemodialysis in hospital in May 2021. JM's health then stabilised, followed by a period of him returning to live at his mother's property. Whilst living with his mother, JM has been offered psychological support and practical assistance in the form of taxis attending his property to transport him to hospital three times a week for dialysis. JM's engagement with this support has fluctuated. He would regularly decline to get into the taxi or simply not be in property (or answer the door). This erratic engagement has, inevitably, put his health at risk of significantly deteriorating, including a risk of death. However, once at hospital JM has, historically, complied with dialysis. During a short hospital admission in September, JM was assessed to lack capacity to make decisions about his treatment for chronic kidney disease. It was identified that JM does not understand his kidney failure is permanent, that his kidneys will not recover and does not understand the purpose of dialysis or the risks and benefits of treatment.

The proceedings

12. On 6th October 2022 the Trust commenced proceedings. Continued efforts have been made to facilitate JM's attendance in hospital for dialysis, including the provision of a support worker from early November 2022 to prompt his attendance. Despite this additional support, including varying the times of the treatment slots to promote his attendance, JM consistently refused to attend hospital. At no point have any coercive measures, such as physical restraint or sedation, been used to secure his attendance at hospital or for the provision of dialysis.

Admission to hospital

13. Between 11th and 18th November 2022, JM was admitted to hospital following concerns about his physical presentation and high blood pressure due to not receiving regular dialysis whilst residing at his mother's home. He accepted dialysis whilst in hospital. By 25th November 2022, JM had missed 3 rounds of dialysis. On 25th November 2022, Dr K (Consultant nephrologist) and Dr C (Renal Consultant Clinical Psychologist) visited JM at home and, following a lengthy discussion, he agreed to travel back with them to hospital. JM then remained as an inpatient in hospital until 20th June 2023. He complied with dialysis treatment without objection three times per week, with additional sessions required due to high blood pressure resulting from non-adherence to recommended dietary requirements. There was no clinical reason for him to remain an inpatient in hospital during this period, save for the fact that he was not fully compliant with regular dialysis when no longer in hospital. JM was assessed to be deprived of his liberty and was made subject to a standard authorisation by the Local Authority on 14th December 2022.

14. In December 2022, the parties agreed and the court endorsed the proposal that it would be in JM's best interests to attempt a trial move to residential care / supported living as an alternative to him residing with his mother. The view taken was that an alternative home environment may increase JM's ability and willingness to attend hospital for dialysis and

support him better to manage his dietary restrictions and take medication. It took several months for the Local Authority to identify long-term options for J. An interim nursing placement, A Nursing Home, was identified, albeit with significant concerns about the age gap between JM and the other residents. The option of a supported living placement was also identified.

Hearing on 19th June 2023

15. At the hearing on 19th June 2023, the parties agreed and the court endorsed, that it would be in JM's best interests to move, in the interim, to A Nursing Home as a "step down" option until a supported living placement became available. On 20th June 2023, JM met with Mrs Justice Roberts (remotely), during which meeting the Judge set out to him the court's decision regarding his best interests, both in respect of the need for continued dialysis and the move to A nursing home. Mr Hadden has told me that the impression of the professionals was that this meeting had gone very well. However, in the early hours of 21st June 2023, JM left the ward without permission. The police were called and he was eventually located at his mother's house. He was persuaded to return to the ward but left hospital again on 23rd June 2023. He was returned to his Mother's home by the Police. On 26th June 2023, JM was persuaded by a support worker to return to hospital, he refused dialysis but agreed to blood tests to be taken, which demonstrated hyperkalaemia (high potassium levels). Dr F, a Renal Consultant, told me that this complication created a real risk of heart and skeletal malfunction which might cause a sudden cardiac arrest which might not be foreshadowed by any symptoms.
16. On 27th June 2023 JM was persuaded to attend hospital for the purpose of a remote visit with Mrs Justice Roberts. He initially refused dialysis but then did agree to a single session and then subsequently became unwell. On 28th June 2023 JM met remotely again with Mrs Justice Roberts but was unwell and uncommunicative. JM was clear that he would leave hospital again when he felt better and would not return for dialysis.
17. Between 26th June and 9th July 2023 there were 11 visits, at home and in hospital, by his main support workers. Their conversations at home succeeded in persuading JM to attend hospital on three occasions. This was largely achieved by ruses, such as a parallel need for blood tests. He consistently refused to attend solely for dialysis. Support workers deployed a technique called "social stories" to encourage JM to attend, but to no effect.

Hearing on 29th June 2023

18. At an urgent hearing on 29th June 2023, the parties agreed, and again, the court approved that, in light of JM's consistent opposition and increasing disengagement, it would be contrary to his best interests to move to A nursing home.
19. On 7th July 2023, JM appeared very unwell. The support worker and social worker who had attended his property were able to persuade him to attend hospital for a blood test. On attending, JM refused dialysis but agreed to a hospital admission. Following admission, JM experienced vomiting and diarrhoea symptoms, which are common when he has not had dialysis. His blood pressure was exceptionally high (~225 / 150); his blood haemoglobin level was normal (120 g/L); his serum potassium was 6 micromol/L (high but not dangerous). JM had mild abdominal pain, fever and other indicators of infection. An

abdominal ultrasound showed no evidence of appendicitis. Two different bacteria in blood cultures were identified from his dialysis line.

20. JM was not re-dialysed over the weekend of 8th- 9th July 2023 to allow for the infection to settle as much as possible. He was prescribed Lokelma over the weekend to assist with keeping potassium levels down. JM was treated with intravenous antibiotics through his dialysis line to increase the chance of eradication of any bacteria on the inside of the line.
21. On 10th July 2023, JM agreed to dialysis after continuing to feel unwell. I highlight this fact because it, to my mind, may resonate with JM's present circumstances. Dr F and Dr C have suggested that when JM's false belief system is confronted by pain, discomfort and ill-health, JM may yield to treatment. At present, Dr F considers that JM is in the early stages of what will become a dramatic deterioration. It also requires to be recorded that JM was sick after dialysis on the 10th July. This was due to his not having received dialysis for some time. "Dialysis Disequilibrium" sometimes occurs when people start, or restart, dialysis when their blood has exceptionally high levels of accumulated toxins. It is transient, and usually settles after 24-36 hours. It is not a prominent or common complication when dialysis is done regularly. Clinicians were concerned that this reaction would simply compound JM's view that dialysis is not beneficial for him. Should JM change his present, seemingly entrenched position, this remains a concern.

Hearing on 17th July 2023

22. JM's circumstances were reviewed by Mrs Justice Roberts on 17th July 2023. At that time JM was still suffering a polymicrobial infection but was improving and accepting of (but verbally declining) dialysis. The court approved the updated Escalation and Behaviour Policy. It was agreed that JM would be encouraged to remain in hospital and to accept dialysis in a more prescriptive, directed manner. In the event of him leaving hospital, JM would continue to receive a package of social care for 21 hours per week (3 hrs x 7 days).

Recent events

23. The infections to the dialysis line were successfully treated. JM remained in hospital until 9th August 2023 when he returned home after receiving dialysis. On 11th August 2023, an ambulance was called to JM's home address at 10am. He was found in bed covered in blood. On inspection, one of the central venous catheter lines used for dialysis access had been cut and was bleeding.
24. JM was admitted via the Emergency Department at a local hospital and transferred to the renal unit at current hospital. It was established that the line has been damaged beyond use and would need to be removed urgently to reduce the high risk of further bleeding from the line. JM consented to the removal of the line but refused the insertion of a new one. He agreed to remain in hospital for a few days to allow the access point of the line to heal over now it is removed but has refused a further line insertion. It was explained to J, in what I am satisfied was clear and entirely unambiguous language, that without further dialysis he will die. He was again told expressly that he will require a new line to be re-inserted if he is to survive. Psychology and speech and language therapist have used communication aids to help explain likely timescales and how hospital will support him as his body dies. They have explained risk of heart attack or stroke. They have explained he can request a line at any time while he is awake. He said he doesn't think he will request a line as he believes

he will not die and he doesn't want dialysis. JM stated, very confidently, that he would not consent to a replacement line and that he was no longer going to undertake dialysis. He expressed the belief that "*nothing bad will happen*"; he won't become "*ill with bugs*" and he "*won't die*". He was asked what happens when he misses dialysis and could he recall that he had become ill with a bug. He said sometimes he becomes ill with a bug but sometimes he does not and that he had not needed dialysis or a line as a child, so he did not need it now.

25. A best interests meeting was convened later that day, attended by Dr C, Dr F and the social worker from Nottingham City Council, his Independent Mental Capacity Advocate as well as other nursing and specialists from the learning disability team.

Prognosis and treatment options

26. In the absence of a new dialysis line being inserted, JM will become more unwell and die. It is expected that he would die. Dr F considers that death is likely between one week, and ten days, after his last dialysis. His last dialysis treatment was on Wednesday 9th August. Death may be preceded by coma, but there is nevertheless a risk of more sudden death at an earlier stage due to hyperkalemia (high potassium levels). JM is currently receiving medication to reduce his potassium levels, although these are not being monitored as it is felt that it would not alter his management.

27. At the best interests meeting, five treatment options were considered:

- a. Chemical restraint (i.e., general anaesthetic) to enable the reinsertion of the dialysis line and thereby enable reinstatement of regular dialysis. Allow JM to go home.
- b. Chemical restraint (i.e. general anaesthetic) to enable reinsertion of dialysis line, and re-instatement of regular dialysis. Detain in hospital (by physical or chemical means if need be) until an alternative secure environment can be found. Would still require transport to/from dialysis on an ongoing basis.
- c. No immediate plan for further dialysis and palliate. Offer dialysis if he is visibly deteriorating. If, at any point, he agrees to dialysis we would undertake line insertion (and other active treatments required alongside that). Still attempt to treat him in his best interests if he ceased to object or become unconscious.
- d. No immediate plan for further dialysis and palliate and continued offer / encouragement to accept dialysis. Gently – and in an appropriate manner – offer dialysis if he is visibly deteriorating. If, at any point, he agrees to dialysis we would undertake line insertion (and other active treatments required alongside that). No attempt to insert a line or otherwise treat, if he ceases to object or if he becomes unconscious. A DNACPR would be in place unless he agreed to dialysis and line insertion, in which case it would be revoked.
- e. No immediate plan for further dialysis. Palliative care pathway. No attempt to discuss further dialysis or active treatment with him. At any point, if he requests dialysis we would undertake line insertion (and other active treatments required alongside that).

This hearing (Tuesday 15th August 2023)

28. Though there was a high level of consensus, the gravity of the issues required exploration. As I have foreshadowed, I heard from Dr F, Dr C and from JM's mother. It was clear that each of them had given JM's circumstances an enormous degree of careful thought. Dr C was able to give me a powerful insight into JM's complex functioning. Dr F, who had been prepared to contemplate some degree of restraint to save his patient, had arrived at the clear and carefully articulated conclusion that such would be "*a short-term measure for a long-term problem*". Dialysis lasts for at least 4 hours at each session. To apply restraint would, both Dr C and Dr F told me, cause JM very considerable distress. It would also compromise JM's easy, comfortable and trusting relationship with the hospital staff. It requires to be said it would cause the treating clinicians and nurses very considerable distress too. In view of JM's early life experiences, it might even retraumatise him. In my judgement, it would compromise JM's dignity.

The Law: Overarching principles

The General Position

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

*"(i) **The doctor, exercising his professional clinical judgment, decides what treatment options are clinically indicated (i e will provide overall clinical benefit) for his patient.** (ii) He then offers those treatment options to the patient in the course of which he explains to him/her the risks, benefits, side effects, etc involved in each of the treatment options. (iii) **The patient then decides whether he wishes to accept any of those treatment options and, if so, which one.** In the vast majority of cases he will, of course, decide which treatment option he considers to be in his best interests and, in doing so, he will or may take into account other, non-clinical, factors. However, he can, if he wishes, decide to accept (or refuse) the treatment option on the basis of reasons which are irrational or for no reasons at all. (iv) If he chooses one of the treatment options offered to him, the doctor will then proceed to provide it. (v) If, however, he refuses all of the treatment options offered to him and instead informs the doctor that he wants a form of treatment which the doctor has not offered him, the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (i e he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion." (emphasis added)*

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

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

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

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

“18. ...[The court’s] role is to decide whether a particular treatment is in the best interests of a patient who is incapable of making the decision for himself.

...
19. ... Generally it is the patient’s consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment...

...
22. [T]he focus is on whether it is in the patient’s best interests to give the treatment, rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it...” (emphasis added)

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

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

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

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

*“35. The authorities are all agreed that **the starting point is a strong presumption that it is in a person’s best interests to stay alive.** As Sir Thomas Bingham MR said in the Court of Appeal in *Bland*, at p 808, “A profound respect for the sanctity of human life is embedded in our law and our moral philosophy”. Nevertheless, they are also all agreed that **this is not an***

absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.

*36. The courts have been most reluctant to lay down general principles which might guide the decision. **Every patient, and every case, is different and must be decided on its own facts.** As Hedley J wisely put it at first instance in *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as *Bland*, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time." (emphasis added)*

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

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

- 1. human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
- 2. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;*
- 3. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*
- 4. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
- 5. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*

6. *compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.*

[64] Thus, whilst there is and can be no defining characteristic of human dignity, it is clear that respect for personal autonomy is afforded pre-eminence. Each case will be both situational and person specific. In this respect there is a striking resonance both with the framework of the Mental Capacity Act 2005 and the jurisprudence which underpins it. The forensic approach is 'subjective', in the sense that it requires all involved, family members, treating clinicians, the Courts to conduct an intense focus on the individual at the centre of the process. Frequently, it will involve drilling down into the person's life, considering what he or she may have said or written and a more general evaluation of the code and values by which they have lived their life.

Best interests

35. Where a person is unable to decide for himself, there is an obligation to act in their best interests: s.1(5) MCA 2005.
36. Where a decision relates to life-sustaining treatment, the person making the decision must not be motivated by a desire to bring about death: s.4(5) MCA 2005.
37. When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence their decision if they had capacity, and to the other factors that they would be likely to consider if they were able to do so: s.4(6) MCA 2005.
38. Account must be taken of the views of anyone engaged in caring for the person or interested in their welfare: s.4(7) MCA 2005.
39. Carers, including health professionals, are permitted to carry out acts in connection with personal care, health care, or treatment of a person who lacks capacity to consent: s.5 of MCA 2005. It provides a significant degree of protection from liability, provided that the act is done in the reasonable belief that capacity is lacking and that the act is in the persons best interests.
40. The provisions of ss.15 to 17 MCA 2005 give the court power to make decisions about personal welfare and to make declarations and orders in respect of a person who lacks capacity. Section 15 deals with declarations, including declarations as to the lawfulness or otherwise of any act which has been or is to be done. Section 16 enables the court,

by making an order, to make personal welfare decisions for a person without capacity, and, by section 17, the court's power in this regard extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care.

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

MCA 2005 Code of Practice

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

"5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment".

"5.33 ... Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests"?

"5.38. In setting out the requirements for working out a person's 'best interests', section 4 of MCA 2005 puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests ..."

“5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)”

Best interests

43. The situation for JM has progressively deteriorated. I remind myself that in early 2023 when JM was clinically stable in hospital, the proceedings were concerned with finding a placement from which he could be encouraged to attend for dialysis three times per week. The situation is plainly now far graver. Restraining JM to reinsert a new dialysis line against his will might in and of itself be justifiable. However, JM’s objection is not merely to the reinsertion of the line but to the life sustaining dialysis it would provide. It follows, inevitably, that the restraint required for the reinsertion would be a harbinger for repeated and extensive restraint on a weekly basis and indefinitely. JM’s erratic compliance and distorted thinking, now over many months, effectively discounts him, I have been told, from eligibility for a donor organ. Such transplant would need compliance with a fairly rigorous regime of support which is very unlikely to be complied with. Moreover, that too may involve an extensive period of haemodialysis.
44. JM’s belief system in respect of dialysis is so plainly distorted as to manifestly rebut the presumption of capacity, erected by the MCA 2005. However, even though his reasoning is unsound, JM’s confidence and belief in his own judgment is well-established and as the chronology of the case has demonstrated, unmoveable. The fact that an individual’s views may be misconceived does not, however, deprive him of the right to hold them. To approach this otherwise would particularly discriminate against the incapacitous, as well as more generally. JM’s views on dialysis arise from the complex interplay of his psychological functioning and his life experiences. This is no doubt true for all of us but in JM’s case, both are disordered. The nature and extent of JM’s autism coupled with the extent of trauma that he has endured, serves to disable him from processing his thoughts and experience in an effective way. Nonetheless, JM’s own reality, even though it greatly differs from ours, requires to be respected. It is in this way that the autonomy of the incapacitous is respected. That does not mean that their views prevail but it does mean that they must be afforded weight. As I have set out above, *“human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition”*.
45. For the reasons which I have set out, I am clear that forced restraint either in the face of JM’s expressed opposition or at a time when he is no longer able to resist, would compromise his dignity. By agreement and because Roberts J had previously met with JM on a number of occasions, I spoke with him on a private video link from which the public and lawyers were excluded. The solicitor for the Official Solicitor took a note. With outstanding efficiency, the note was available to the parties within 20 minutes of my concluding the meeting. Judges, I suspect, vary greatly in their approach to meeting with P. Video conferencing platforms have changed the landscape. It seemed to me, ultimately unthinkable, that I should not meet with JM and tell him the important decision I had made. I found him, as has everybody else involved in his care, to be a

very pleasant young man. His conversation with me reinforced Dr C's assessment of him. As both Dr F and Dr C have said, JM does not want to die. When I told him of my decision and the fact that he would die, he told me without prompt or question that he did not want to. I formed the impression that he very much wanted to live. Ultimately, all I could do was tell him that the decision was his.

46. I should like to pay tribute to the doctors and nursing staff. As Ms Roper KC has submitted, "*the clinicians have been exceptional in the compassion they have shown for JM and the dedication with which they have tried to help him understand his situation*". I agree. I should also like to pay tribute to JM's mother and sister. Though JM's mother struggles to understand the realities of JM's situation due to her own mental health difficulties, she has an impressive and, I sense, strongly maternal instinct that the use of restraint to compel dialysis would be inimical to his welfare. Those instincts, to my mind, are sound and also require to be factored in to this decision.