IN THE COURT OF PROTECTION
[2019] EWCOP 46

COP 1349079

Royal Courts of Justice
Strand
London, WC2A 2LL

Friday, 9 August 2019

IN THE MATTER OF THE MENTAL CAPACITY ACT 2005

Before:

MR JUSTICE COBB

B E T W E E N :

UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST — Applicant

- and -

RR — Respondent
(By his litigation friend the Official Solicitor)

MS N. KHALIQUE QC (instructed by the Trust) appeared on behalf of the Applicant.

MR J. MCKENDRICK QC (instructed by the Official Solicitor) appeared on behalf of the Respondent.

J U D G M E N T

MR JUSTICE COBB:

1 It is difficult to imagine a sadder reason for convening a court hearing but I am asked today, using powers vested in me under the *Mental Capacity Act 2005*, to make declarations in relation to a young man, who I shall refer to as "RR", specifically in relation to easing his passing. Specifically, first, I am asked to consider his capacity to make decisions around his care for himself; and, secondly, if I find that he lacks capacity, I am asked to consider and, if appropriate, approve a palliative care plan to allow him to die, (which is likely to be in the next few days), with the minimum of pain and stress.

2 RR is currently at home with his father, having been discharged yesterday from the William Budd Ward at the Royal United Hospital in Bath. He is twenty years old. RR is very poorly indeed. He has severe aplastic anaemia, a condition from which he has suffered for approximately five years and from which he will not recover. He is said to have a matter of days, or possibly weeks, to live.

3 There was a discussion earlier today about whether this hearing was absolutely necessary. On balance, it was felt that it *was* so that there would be total clarity about the lawfulness of the steps proposed. I do not have the luxury of time, I understand, to reflect on what I have heard or read. RR and his family and those charged with the task of caring for him need to have a decision today. I give this judgment, *ex tempore*, accordingly.

4 Earlier this summer, RR underwent a bone marrow transplant. This failed to achieve the desired recuperative outcome. Since then, RR has suffered serious neutropenic sepsis and other life-threatening infection. When the matter was brought before me earlier this week, RR had not long been discharged from the intensive care unit. The relevant NHS Trust brought the application, seeking a declaration that it would be unlawful to give RR a second bone marrow transplant or, put another way, that it would be lawful not to give him this further transplant.

5 The case was before me on Monday 5 August for directions, and I listed the hearing for today (9 August), appreciating the urgency of the situation. The Official Solicitor was invited, and graciously accepted the invitation, to represent RR in these proceedings. Over the course of the last four days, further evidence has been collated. Sadly, during the course of the last few days, RR's condition has deteriorated.

6 What do I know about RR? He is described in a medical report written in 2014 as "a delightful young man", and from all that I have read, I am sure that that description is as sound now as it was five years ago. From my acquaintance of RR, only through these documents, I have come to know him as a worldly, thoughtful, humorous young man, an independent soul with a free spirit and loyal friends.

7 RR has undoubtedly encountered very considerable adversity in his life. His early years were characterised by significant harm while in the care of his birth family. His mother and sister are said still to have had (and continue to have) mental health issues. He was taken into foster care where it is said that he was sexually and physically assaulted by his foster carers. He was treated as a young person for ADHD and attachment disorder. Through his middle and later childhood, RR has displayed behaviours consistent with a complex mix of emotional and psychological conditions, variously described in the documents as autism, Asperger's syndrome, dyspraxia and traits of an emotionally unstable personality disorder. Some of these labels may, and some may not, be helpful or accurate but in fact they tend to tell us a little of his behaviours and his challenges.

8 In so far as he displayed signs of emotional dysregulation, and there was much evidence that he did, Professor Sensky, to whom I shall return later, told me that this was likely to be attributable to the significant childhood trauma suffered by RR. He has been a regular user of non-prescribed drugs, mainly cannabis. He is a smoker of tobacco. He has suffered periodically from low mood, occasionally bouts of *very severe* low mood.

9 RR was adopted successfully at the age of seven or eight and benefited, it seems to me hugely, from the life his (adoptive) father was able to give him. Recently RR said to his adoptive father (TR) "Thank you. Because of you, I was able to be an adult." A poignant and, in the circumstances, utterly tragic observation from a very young man whose life is ebbing away.

10 Notwithstanding the challenges of living a life with these conditions, RR was able to live independently for the last two years. He has enjoyed a meaningful relationship with a girlfriend, who has visited him in hospital and who has made her views about his case known to me through the Official Solicitor's representative.

11 There is no real purpose to be served in me rehearsing in any great detail the medical history of RR over the last five years, or indeed even over the last ten to twelve months. It is

sufficient to note that his condition, aplastic anaemia, was first diagnosed in 2015, and at that point it was successfully treated. Earlier this summer, as I have indicated, RR underwent a cell stem transplant. This was unsuccessful regrettably, at least in part because RR did not consistently follow the required care and treatment plan.

12 At a best interests meeting held on 19 July 2019, the medical staff charged with the responsibility of caring for RR concluded unanimously that there was such an unfavourable prognosis for a second bone marrow transplant that it should not be attempted. A major contributing factor in their decision was the expectation that RR himself would be unable to adhere strictly to the required lengthy and complex care plan. Therefore, as I say, it was, in those circumstances, that the NHS Trust issued its application for declaratory relief under the *Mental Capacity Act 2005* in relation to RR's treatment.

13 **Capacity**: I turn to the question of RR's capacity. The *2005 Act* of course can only be properly invoked or applied if the court finds that the subject of the application lacks capacity to make the relevant decision. I do not consider it appropriate, or indeed necessary, for me to set out the statute law extensively as it is contained in the *2005 Act*. I proceed, as I should, on the basis that a person must be assumed to have capacity unless it is established that he lacks capacity. Put another way, that subsection implicitly requires the NHS Trust here to demonstrate, on the balance of probabilities, that RR lacks capacity. A person is not to be treated as unable to make a decision merely because he makes an "unwise" decision is another significant principle in the opening section of the *Act*.

14 In *s.2(1)*, it is provided as follows:

> "For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.
>
> (2) It does not matter whether the impairment or disturbance is permanent or temporary."

I may say, again without reproducing in this judgment all of the subsections of *s.2*, and then again *s.3*, that I have had very much in mind the requirements of the *2005 Act* when reaching my decision.

15 It perhaps is appropriate that I should nonetheless emphasise that "at the material time" means now, it means today. The decision that is the subject of this application is a decision in relation to treatment and I have to be satisfied, on the case advanced by the NHS Trust, to the balance of probabilities, that a person's lack of capacity is "because of" an impairment or a disturbance in the functioning of the mind or brain. I have those points very clearly in mind.

16 Unsurprisingly, the statute has been considered and significantly interpreted over the years since 2005 and the relevant law is now admirably rehearsed in the judgment of MacDonald J. in the case of *Kings College NHS Hospital v C & V* [2015] EWCOP 80. My judgment today should be deemed to include that extensive section of the judgment from paras.25 to 39, which have been reproduced *in extenso* in the submissions of Mr McKendrick QC. I may add that the case law overall has been admirably considered, reproduced and, of course, agreed by both advocates.

17 The question arises whether RR has capacity or not to make the decision about his treatment. It is fair to say that it is only in recent days, or possibly weeks, that a question (or significant question) has arisen over his capacity, and that question has arisen as his life hangs ever more delicately in the balance. Because the issue has only arisen in recent days or weeks, I am conscious that I need to be particularly vigilant to ensure that those who are looking after RR professionally have not come to a conclusion about his incapacity out of expediency or because they have, for instance, applied the wrong criteria, or because they have been overwhelmed by the palpable tragedy which surrounds RR and his situation.

18 Capacity has, to a greater or lesser extent, been considered by a number of medical clinicians, doctors, over the course of the last months and I have been taken, during the course of this hearing, to assessments by Dr Robinson, Dr Moran, Professor Marks and Dr Protheroe among them. The issue has been addressed by clinical nursing staff both in the hospital and in the community. Mr McKendrick has helpfully and rightly drawn my attention to the progression of assessments over recent months, drawing specific attention during the course of the cross-examination of Professor Sensky to a discussion with RR as recently as 24 July, which might, suggested Mr McKendrick, have demonstrated that RR was then likely to have been capacitous. The assertion was made because the conversation, says Mr McKendrick, between RR and the relevant nurse showed RR to possess and display a degree of insight and understanding of his condition and its impact on those around him

and, argues Mr McKendrick, when in the right frame of mind, it is apparent that RR can indeed take on and rehearse for himself the relevant information.

19 Within the documents filed on this application there is to be found a statement from Dr Paul Moran, honorary consultant psychiatrist employed by the University of Bristol. In a statement dated 1 August, Dr Moran set out his understanding of RR's condition and, on the basis of a meeting with RR and a review of records, Dr Moran concluded that RR, while he may have understood what the further treatment involved, had impaired ability to retain, recall, use or weigh that information. At para.20 he concluded:

> "At the time of my assessment, I concluded that [RR] was unable to retain information relevant to the treatment decision and unable to use and weigh information as part of a decision making process as a result of his adjustment disorder and underlying traits of an emotionally unstable personality disorder."

20 It is said that Dr Moran made that assessment perhaps on incomplete information and, in fairness, neither the applicant nor the Official Solicitor place any or any significant reliance on that report. I have evidence from Dr Rachel Protheroe, consultant in adult bone marrow transplant, employed by the University Hospitals Bristol NHS Foundation Trust. She has held responsibility for treating RR for his condition. In a statement dated 1 August 2019, she tells the court that:

> "[RR] is unable to understand the information relevant to the decision about his treatment. He is unable to understand the complexity of what the treatment would involve and the risks and consequences of his non-compliance with treatment relevant to these proceedings."

21 She has taken the view that RR cannot use or weigh information about his treatment, including the risks of second transplant, partly due to his emotional lability and impulsive behaviour. He lacks insight and understanding of the fact that he has a problem in respect of which he needs advice. That witness statement is supported in terms by a certificate as to capacity completed by Dr Protheroe on 26 July.

22 Entirely properly, the Official Solicitor, when she was first invited to act for RR, requested my permission to instruct an independent expert to assess this important question of capacity and she instructed Professor Sensky. He is an Emeritus Professor of psychological medicine at Imperial College, London and consultant psychiatrist at West London NHS Trust. He has considerable experience in the application of research evidence to clinical practice and was,

until relatively recently, a medical member of the First Tier Mental Health and Social Entitlement Tribunals.

23 He reviewed the documents and paid a visit to RR on Tuesday, 6 August, in fulfilment of his instruction. He prepared a detailed and thoughtful report, which questioned some of the earlier diagnoses and confirmed others. I have his report, which I have read with care. Without seeking to diminish the significance of much of that report, I think it is appropriate to focus on paras.39 to 46 inclusive, as set out below:

> "**39** Information from the GP records indicates that [RR] has been diagnosed by a specialist as having Asperger's syndrome. Emotional dysregulation is not a feature of Asperger's, but Asperger's is likely to make communication and emotional regulation more difficult. For example, the rigidity of thinking found in people with Asperger's is likely to make it harder for a person to develop more adaptive responses to stress (Dr Dunkerley's example of RR's response to his injured elbow might fit with this, for example). The observation that [RR] does not wish to talk about the past is also consistent with this.
>
> **40** Emotional dysregulation is expected in emotionally unstable personality disorder, but I was able to find to reference in the documents available to me to this diagnosis having been made by a specialist. A history of self-harm is a characteristic feature of emotionally unstable personality disorder and although such a history is noted in [RR]'s recent records, I could find no relevant reports in his GP records. In my opinion, there is insufficient evidence to make this diagnosis.
>
> **41 [**RR] was certainly given a diagnosis of attachment disorder when he was a child. This is very likely to have been caused by the abuse and other traumatic experiences he had in childhood. However, a search of the published literature failed to identify a clear association between attachment disorder and emotional dysregulation. Attachment disorder, if it continues into adulthood, usually involves pervasive maladaptive behaviours. From the information available to me, it appears that [RR]'s maladaptive behaviours are not longstanding and pervasive, but situational. For example, his behaviour when his aplastic anaemia was first diagnosed, or even before the first transplant, was evidently quite different to his behaviour more recently, because he did not previously have such distressing emotions to try to cope with. Therefore I do not think that attachment disorder contributes substantially to the current clinical picture.
>
> **42** Dr Moran raised the possibility of an adjustment disorder being present. By definition, adjustment disorders follow distressing life events, and [RR]'s failed transplant certainly qualifies as such. Also, [RR] has shown distress and anxiety, which occur in adjustment disorder. However, other features of adjustment disorder are absent, such as persistent sleep or appetite disturbance (I could find no references to these in the medical records). For this reason, I do not think [RR] presently has an adjustment disorder.

[RR]'s capacity to make decisions about his treatment and litigation capacity

43 In my opinion, there is no doubt that [RR] has an impairment of, or a disturbance in, the functioning of his mind or brain. However, I find it impossible to give a single ICD-10 diagnosis for this disturbance. My preferred formulation, based on the information available to me, is of major problems of emotional dysregulation due to childhood trauma, compounded by Asperger's syndrome (see above). Dr Moran's diagnosis of traits of emotionally unstable personality disorder is consistent with the crucial importance of emotional dysregulation.

44 This formulation is very likely to impair [RR]'s capacity to make decisions about his treatment, particularly in weighing relevant information in the balance and in communicating his decisions. [RR]'s poor ability to manage distressing emotions and his pattern of using maladaptive coping strategies is likely to result in his being unable to reflect on aspects of his treatment which cause particular distress. Rather than thinking about such aspects or talking with someone about them, [RR] will do whatever he can to avoid them. As a consequence, it is very unlikely that he can base any decisions on all the relevant information available to him. [RR]'s evident reluctance to talk (and presumably also think) about the past also contributes to this, in that future decisions are commonly based, to some extent at least, on past experience. In addition to their effect on using information, the thinking mechanisms just described will affect his ability to convey his decisions to others and more particularly to consider other options where necessary. For the same reason, the mechanisms just described are likely to interfere with his ability to conduct proceedings. If he is striving not to become overly distressed, it can be predicted that he will try at least sometimes not to pay attention to distressing information he is being given. This is likely to interfere with his registering such information.

45 The processes just described are not amenable to change using any short-term intervention. [RR]'s autistic traits could be modified with long-term therapy and coaching, but there is no likelihood that they would respond to a brief intervention, even if [RR] was amenable to such an intervention. Emotional dysregulation also requires long-term therapy. As [RR] noted in his interview with me, particular types of interaction can exacerbate [RR]'s distress and therefore make it more likely that he will employ his usual maladaptive coping strategies. There are evidently some people who are better able to engage with him than others. However, in my opinion, even if it were possible to engage [RR] optimally, the problems described above would persist. In other words, in my opinion, optimising the interaction of staff with [RR] would still leave him with impaired decision-making about his treatment.

46 Regarding [RR]'s capacity to make decisions about his treatment, I would also note that his adoptive father understandably has strong views. My interview with [RR] and his father indicated that father has tried to persuade [RR] to adopt his father's views."

24 Particular emphasis was drawn in the course of his evidence to paras.43 and 44. At para.43 he advised that RR displayed evidence of major problems of emotional dysregulation due to childhood trauma, compounded by Asperger's syndrome. He told me in his oral evidence that children who are persistently traumatised are unable to develop healthy coping strategies. They develop maladaptive strategies which then translate into negative behaviours and, he said, looking at RR's behaviours and presentation, this was entirely consistent with this conclusion.

25 As indicated above, at para.44, he went on to say that such a formulation is "very likely to impair RR's capacity to make decisions about his treatment, particularly in weighing relevant information in the balance and in communicating his decisions".

26 In oral evidence, in answer to questions from Mr McKendrick, he emphasised those four factors: first, poor ability to manage distressing emotions; second, patterns of using maladaptive coping strategies; third, inability to think about the past or maybe, he said, it is better described as a *choice* not to think about the past; and fourth, a possible inability to talk about the past with someone.

27 Significantly, in my judgment, Professor Sensky said that these characteristics would not "necessarily be pervasive and they may appear as patterns." He went on in para.45 to say that "the processes are not amenable to change using any short-term intervention" (see above).

28 As indicated above, Professor Sensky gave oral evidence before me. He was questioned by counsel. He confirmed that he had seen the medical records, to which he was then taken in more detail, particularly by Mr McKendrick. He was asked specifically about RR's coping strategies. He told me that RR's developed strategies were not satisfactory. All they had done was to help him, RR, to create distance from distressing emotions but were not helpful to him in decision making as they were essentially avoidant. He considered that the coping mechanisms which RR has described he uses are essentially different forms of withdrawal from decision making, which, in Professor Sensky's view was "essentially maladaptive." Professor Sensky illustrated this with examples, first of RR disappearing from the ward in the past, which was of course dangerous for RR to do. Time away was useful, reflected Professor Sensky, but it was also maladaptive.

29 Professor Sensky went on as follows, and this is my note of his evidence:

> "He has not been able to use the experience of the first failed transplant and that is problematic. This is an example of maladaptive behaviour. He has an inability to manage his emotions except by switching off. That makes the discussion with him particularly difficult. People with Asperger's are rigid in their thinking and cannot consider their options flexibility. [RR] has a particular view about the treatment he was receiving for his elbow…

Professor Sensky went on to say how RR had a firm view about how his elbow should be treated which was not consisted with the medical opinion. The strategies he deploys to deal with increasing anxiety are, he said, the problem. He may have been able to consider past history but is not generally willing to discuss past history.

30 Professor Sensky agreed with Mr McKendrick that there was evidence of RR being able to reflect and show insight into a number of stresses in his life, including a pregnancy and miscarriage of his girlfriend. Professional Sensky was taken specifically to a note of the interview or meeting on 24 July. I gave Professor Sensky the lunch break to read it carefully to himself. He said this when asked about it:

> "I struggle with this. There are undoubtedly points at which it has been possible to have calm discussions with [RR] and when it has been possible to see that he has understood aspects of his situation. I am still not sure whether this applies to the moment at which he needs to make decisions, however. When he is calm and when he is engaged with someone he trusts, he can exchange information and he is aware of relevant information that he needs to consider but this does not go as far as identifying that he has made a decision."

31 I pause there to say that he had earlier told me that what we see on 24 July does not indeed tell us anything about RR's decision making. He added:

> "He wants to be autonomous. I am still uncertain whether the factors in para.44 would be irrelevant in his finally trying to reach a decision but the setting is all important."

32 Going on again in relation to this interview, on which focus was brought, he said this:

> "That interview is striking but I do not think it covers all the aspects of decision making. It does not cover him giving a decision. I cannot say what processes have been involved."

33 In answer to a question from me wherein I had specifically refocused Professor Sensky to the fact that the time at which the question of capacity has to be considered is "at the material time", i.e. by agreement now, he said this:

> "As anxiety increases, the reality is that the four factors (those are the four factors referred to in para.44) are more likely to be prominent."

34 Mr McKendrick on behalf of the Official Solicitor presents a strong argument that the presumption of capacity has not been displaced. He argues that RR has been treated as having capacity until or around the middle of July. The fact that RR is now so fearful of what lies ahead for him is not a reason for saying that he lacks capacity and a fear and terror of his immediate future is not of course attributable to his impairment of or disturbance in the functioning of his mind or brain.

35 I have to say that this has not been a straightforward or easy decision. I have had to consider, on the evidence before me, what the decision making "at the material time", i.e. now, is, and I have to consider of course the *specific* decision. At the moment, at the material time, RR lies in bed in his father's home, plainly fearful of his imminent death. The decision over treatment is unquestionably fraught with undoubted intense levels of stress and fear. Any twenty-year-old, indeed it may be said any person at all, will be terrified by the very decision which this young man faces.

36 I am satisfied on all that I have heard that as the decision has approached, so has RR's capacity to make that decision diminished. The specific factors on which Professor Sensky relied in indicating that he would lack capacity are directly, in my judgment, and acutely engaged now, perhaps more than ever, and they so significantly compromise his decision making ability, to make this dreadful life/death decision, as to rob him of the capacity to do so.

37 On the basis of all of the evidence, I am satisfied that the Trust has made out its case that at the material time, now, RR does *not* have the capacity to make the decision which is at the centre of this dispute and I am therefore in a position to make a declaration. I would like, before leaving this point, to make one further observation. Neither RR nor anyone close to him should think that there is any disgrace or shame in the fact that I have reached this conclusion. It is an unhappy but nonetheless real consequence of his complicated emotional, psychiatric and psychological makeup, and the dreadful and acute situation in which he now finds himself.

38 **Best interests**: RR is now profoundly unwell. There is no real prospect of a second bone marrow transplant. Even were it not for this recent deterioration in his health, there are

identified in the documents real concerns over whether this would have been in his best interest for a number of reasons:

(i) The specific risks of a haploidentical, that is a half identical, donor, including the discomfort and risks caused by cytokine release syndrome, the high risk of graft failure, the risk of graft versus host disease.

(ii) The need for RR to remain in isolation for four weeks for the second allograft and the preparatory treatment including chemotherapy, when I know, and RR has himself said many times, he would not be able to tolerate such a regime, even with the selfless support of his father.

(iii) Cytokine release syndrome.

(iv) Regular follow-up tests and medication over nine to twelve months. Again, I know from recent history that RR has been unable to maintain a regime of treatment over a relatively short, a much shorter, time than that.

(v) The low success rate: given that it is a second graft with a haploidentical donor, somewhere close to one per cent.

(vi) That in a non-cooperative patient, and I pause there to say that I regret to say RR is such, a second transplant is likely to be futile, with associated risks of death and toxicity from transplantation in addition to those of aplastic anaemia.

39 In reaching a best interest decision in relation to him, I must take into account RR's own views so far as I can ascertain them. It is fair to say that until recently RR wanted a transplant but his discussion with Professor Sensky now casts doubt on that. He said, "They can't do anything for me. I'm not mentally strong enough." Professor Sensky asked whether there was anything that could be done to make him stronger. He said, "No." He told Professor Sensky, "I can't do another two months in hospital. I can't do it, dad."

40 RR's father and RR's girlfriend expressed the understandable but inevitably forlorn hope that RR could receive a transplant but on all the evidence that I have now received and read, it appears that palliation is likely to be best for him. On his behalf, the Official Solicitor makes this submission:

> "Whilst all life is precious, ultimately [RR]'s remaining likely limited further period of life should be as comfortable as possible, to permit him to enjoy his remaining time with his family, his father in particular, his girlfriend and other half-siblings and friends. After careful consideration, the prospect of around a one per cent success rate in respect of a second graft appears insufficiently compelling given it would subject [RR] to arduous treatment in a confined hospital setting which he clearly has struggled with and which could also mean he is unable to see family and friends, given the need for him to be nursed in isolation. Further, such a decision is more consistent with his more recently expressed wish not to have the treatment and his feeling of importance by being with those he loves. The magnetic factors point to allowing him as quality a time with his family and friends as possible."

41 I agree with all of those sentiments and echo them. I propose to grant the declaration sought by the Trust, that it is lawful and in RR's best interests that he be treated in accordance with the palliative care plan which is contained in the papers before the court, with minor amendments that have been discussed.

42 I conclude, as I started, by repeating that it is indeed difficult to imagine a sadder reason for being here. It leaves me only to say this, that this court wishes for RR a peaceful, calm and graceful end to his life and, for his family, strength and comfort in their distress.

43 **Postscript**: RR sadly died a little over 48 hours after this judgment was delivered, on 11 August 2019.

44 A reporting restriction order was made on or about 5 August 2019. On the information available to me at the time of publication of this judgment, I am satisfied that the *Article 8* rights of the family prevail over the *Article 10* rights engaged here, and RR should not be named; no party to the litigation has sought to argue otherwise. It is perfectly proper for this reporting restriction order to endure beyond the death of RR (see *V v Associated Newspapers* [2016] EWCOP 21). I would be prepared however to entertain an application to vary or discharge that order (insofar as it obtains to RR's identity or otherwise), on application by the press or other interested party, and on notice to the parties and/or their representatives.

45 That is my judgment.

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