



Neutral Citation Number: [2020] EWCOP 7

Case No: 13552982

IN THE COURT OF PROTECTION
IN THE MATTER OF THE MENTAL CAPACITY ACT 2005

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 29/01/2020

Before :

THE HONOURABLE MR JUSTICE HAYDEN

Between :

QJ	<u>Applicant</u>
- and -	
A Local Authority	<u>1st Respondent</u>
- and -	
An NHS Trust	<u>2nd Respondent</u>

Mr Oliver Lewis (instructed by **Butler & Co Solicitors**) for the **Applicant**
Ms Victoria Butler-Cole (instructed by **Local Authority**) for the **1st Respondent**
Ms Sarah Simcock (instructed by **Bevan Brittan**) for the **2nd Respondent**

Hearing dates: 29th January 2020

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 on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the respondent and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Hayden :

1. Following the first hearing in this case on 21st January 2020 I gave an ex tempore judgment, now reported at [2020] EWCOP 3. It concerned an application relating to QJ, who is 87 years of age. He is represented by his litigation friend, James Manning, who attended at court on that occasion and, if I may say so, has plainly given the application in this case detailed and anxious consideration.
2. QJ has a diagnosis of vascular dementia. Quite what stage that dementia has reached has been the subject of enquiry. CT scans show him to have experienced a number of strokes. He is extremely frail and, as I observed in my earlier judgment, unable to mobilise without assistance. He has lived in care homes since 8th August 2019 and was moved into his present care home on 26th September 2019. There seems to be no doubt that he lacks capacity to determine where he should live and the care that he should have.
3. However, the issue that has been in focus at this hearing, and the two previous hearings in the last week, is whether QJ has the capacity to determine the nature and extent of any medical treatment. This is an entirely different sphere of decision making. It is a cardinal principle of the Mental Capacity Act 2005 ('MCA') that those responsible, including doctors, care workers, family and the court, must be fastidious to evaluate capacity on an issue-specific basis.
4. The principles to be applied are well known and are set out in s.1 MCA:
 - (1) *A person must be assumed to have capacity unless it is established that he lacks capacity.*
 - (2) *A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.*
 - (3) *A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*
 - (4) *An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.*
 - (5) *Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.*
5. Each of these principles is fundamental to decision-making and each is of equal weight and value.
6. At the hearing on 21st January 2020, I expressed concern as to whether QJ had capacity to influence his treatment or not. Pursuant to s.49 MCA, I directed the Trust to produce a report. This was written by Dr A, a consultant in old age psychiatry, dated 24th January 2020. In it, he expresses the view that QJ has capacity to conduct proceedings, has capacity to decide about nutrition and hydration and to decide about medical treatment, but lacks capacity in relation to residence and care.

7. Dr A also concludes that QJ understands that the court process involves instructing solicitors to act on his behalf. I note that QJ had been communicating with his solicitor to challenge his placement in the care home and that he understood that the case would be decided by a judge. Dr A concluded that QJ was able to retain, weigh and communicate that information. He noted that QJ found it difficult to articulate himself and that *“he tends to shrug, nod, or shake his head in response to questions as his voice has become dry and croaky due to reduced food and fluid intake. He is unable to leave his bed due to presumed muscle weakness/atrophy from weight loss and reduced mobility.”*
8. In relation to questions about residence, Dr A considered that QJ was able to indicate where his home had been, but was unable to recall meeting Dr A on a previous occasion, or how he came to be in a care home. It is noted that he *“minimises the effect his frailty has on his ability to care for himself”* and from this it is extrapolated that he was unable to weigh up the relevant information.
9. After receiving Dr A’s report, the parties sent an agreed letter to Dr A on the same day, setting out the law in relation to capacity to conduct proceedings. Having considered this letter, Dr A speedily wrote an addendum report, also dated 24th January 2020, clarifying that on further assessment he considered that QJ lacked capacity to conduct proceedings.
10. At the second hearing on 27th January 2020, I directed that the NHS Trust be joined and that the treating consultant should file and serve a statement looking at specific issues. In particular I was explicit that the report should address QJ’s capacity in the following spheres:
 - a. To make decisions about nutrition and hydration
 - i. orally;
 - ii. through artificial means;
 - b. To make decisions about medical treatment;
 - c. To make decisions about being admitted to hospital.
11. The treating consultant is Dr B, who is a consultant geriatrician and QJ’s treating physician on the ward. Dr B provided a detailed and extensive report which covered a range of issues. He noted that QJ has symptoms of vascular dementia which have endured since 2017. He indicates the survival rate for this manifestation of dementia is between five to seven years on average. However, Dr B notes that QJ’s advanced age and cardiovascular comorbidities, combined with high dependency and poor nutrition, will, in his view, considerably reduce that life expectancy. He expressed the view that the dementia evaluated at “moderate” in 2018 is at an “advanced stage now”. Dr B expressed that view in clear and unambiguous terms.
12. It was self-evidently recognised by the parties’ lawyers that whilst Dr B set out a detailed consideration of the medical options relating to feeding, there was not the precision of focus on questions of capacity that had been directed by the court. Accordingly, the lawyers required of Dr B a supplementary statement. I express my

gratitude to him for his willingness to assist the court and to prepare challenging documentation at short notice.

13. That supplementary statement is dated 28th January 2020, the same date as Dr B's substantive report. It recognises that QJ had previously been assessed as capacitous to take the decisions that the court was being required to consider. As mentioned in my earlier judgment, QJ's general practitioner, Dr E, had independently come to the same view as Dr A. Dr B was shown a copy of the report prepared by Dr A setting out the reasoning underpinning his conclusions. It has to be said that when Dr A assessed QJ he was at the care home where he had been residing for some months and, accordingly, in surroundings that are familiar to him. That, coupled with Dr A's obvious expertise in supporting QJ's decision-taking, created propitious circumstances for promoting QJ's capacity.
14. Dr B, in the hospital situation, did not have the same advantage. However, Dr B is a consultant geriatrician of very considerable experience. He is the clinical lead for dementia at this NHS Trust. He has held his current post at the Trust for 20 years and he is consultant in charge of QJ's treatment whilst on the ward. He has been involved with the management and care of complex patients with a similar history to that of QJ throughout his entire career as a consultant and prior to that too. Self-evidently, he brings a great deal of experience and expertise to the case.
15. The assessment of QJ's capacity was undertaken on 28th January 2020 at around 9am. Dr B was, as he records, highly alert to the fact that QJ has a significant cognitive impairment. QJ has, for example, a mental test score of 4/10, which is low, and of course there is the long-standing diagnosis of vascular dementia. He had been admitted with a chest infection, which Dr B observed can itself sometimes affect a patient's cognitive state, although he records that the impact of the infection was not obvious when he saw QJ. QJ identified the correct hospital when Dr B asked him where he was. He thought that he had admitted from his home rather than a care home. QJ was asked if he knew why he was in hospital, to which he shook his head and looked at Dr B with what he describes as "*a blank expression*". QJ was prompted by being reminded that he had not been eating or drinking for some time and concerns had been raised about him. He said nothing. When asked if he was hungry, he shook his head. This is a pattern that runs throughout the papers and has been observed by a variety of care home staff and clinicians, as well QJ's litigation friend and his solicitor.
16. Dr B took that response to mean that QJ seemed to understand the questions, even though he was not engaging in speech. Dr B tested him a little further and asked what would happen to him if he continued to refuse food. Previously, and quite recently, QJ had been able to answer that question, but on this occasion he looked blank, starred back and shrugged his shoulders. Dr B pursued it further and explained to QJ that he was likely to die if he did not eat. Dr B observed that QJ appeared entirely unconcerned, but he also noted that QJ seemed to be fully alert and, although he did not reply, he was looking at his interlocutor.
17. One of the options that has been considered is the insertion of a nasogastric ('NG') tube, so it was suggested by Dr B to QJ that this would involve the insertion of a fine tube down his nose that would pass into his stomach to feed him. It was explained that this might improve his condition with regard to food. Dr B explained to QJ that he

might experience considerable discomfort in that process and that there would have to be blood tests, to monitor how he reacted to the tube itself and to the feeding. To this QJ showed no reaction. But, when Dr B gestured to indicate a tube going down his nose, QJ shrugged and shook his head. Dr B records that, “*My impression was that he could understand what I was explaining to him.*”

18. Dr B pursued that and asked QJ to repeat what he had been told concerning refusing food, but he was met again by a blank stare. When QJ was asked whether he knew it would be necessary to put a tube down his nose, he said, “*I know*”, but he did not add anything when challenged which revealed any wider understanding.
19. Summarising what just occurred, Dr B then asked QJ about what he had said a few minutes earlier, but he did not answer at all. He gave Dr B the impression that he could not remember any part of what the doctor had said. Dr B reported that QJ gave Dr B no impression that he was able to weigh up the information that he had been given. He would occasionally shake his head, but not verbalise any detail. This led Dr B to come to this conclusion in his supplementary statement:

“He did not seem to understand the gravity of what might happen to him if he did not eat and would barely talk although he was capable of speaking. It may be that he simply did not want to talk to me but my judgment was that he did not really understand the consequences of his action and could not communicate any view other than by occasionally shaking his head. I did not feel that he had any real depth of understanding of his situation. I could not get him to describe why he was in hospital, nor could I get him to even repeat minimally what the concerns about him were. I did not sense any evidence of him being able to weigh up or retain the information given to him.”

20. Dr B was entirely aware that others had regarded QJ’s response and resistance to eating and drinking as a form of “*silent protest*”, but he commented that a refusal to accept food and drink is “*a common feature of the sort of illness that QJ suffers from*” and is one that he had encountered many times in the course of his work.
21. I have struggled to understand those conclusions, not only in the light of the totality of the available evidence, but also in the context of Dr B’s own observations. It is undoubtedly a difficult situation when an individual suffering from dementia chooses not to respond to certain questions. However, we do know that QJ has chosen not to eat for many weeks. We know that prior to that there had been a significant decline in his food consumption and we know that presently, at hospital, he is taking miniscule amounts of food and Fortisips as well as water.
22. Dr B was himself satisfied that QJ did not want the NG tube and that there were significant questions relating to eating and drinking that he was also satisfied QJ understood.
23. Whilst I of course recognise Dr B’s experience and expertise, and entirely accept his view that a refusal to accept food and drink might well be a common feature of the sort of illness that QJ suffers from, I am required to evaluate QJ’s capacity in relation to these specific issues, and I do so. I am highly conscious that the presumption of

capacity is a fundamental safeguard of human autonomy. It requires cogent, clear and carefully analysed information before it can be rebutted.

24. It is important to emphasise that lack of capacity cannot be established merely by reference to a person's condition or an aspect of his behaviour which might lead others to make unjustified assumptions about capacity (s.2(3) MCA). An aspect of QJ's behaviour included his reluctance to answer certain questions. It should not be construed from this that he is unable to. There is a good deal of evidence which suggests that this is a choice.
25. All parties in this case agree that evaluating capacity on this specific issue is finely and delicately balanced. But ultimately, I have to be satisfied, on the balance of probabilities (s. 2(4) MCA), that the presumption has been rebutted. I am unable to reach that conclusion.
26. It is potentially significant, and certainly interesting, that the agreed medical consensus as to the way forward accords exactly with what QJ himself expresses. Firstly, QJ is, as I have mentioned, accepting the Fortisip. Nobody suggests that this could sustain him long term. Having regard to the extent to QJ's dementia and the applicable NICE Guidelines,¹ which emphasise that there is "*no good evidence that people [in these circumstances] who had tube feeding lived any longer than people who did not*", Dr B considers that an NG tube is unlikely to prolong life-expectancy in any way. Moreover, the fitting of the tube is highly distressing, extremely invasive and uncomfortable. QJ has clearly indicated that he does not want it and it is realistic to assume that he may try to remove it, as patients in these circumstances so frequently do.
27. Looking more generally at the options, the NG tube also carries a risk of infection and it cannot be properly regarded as a long-term intervention. Only a percutaneous feeding ('PEG') tube could be fitted. That carries significant risk of morbidity and would provide only a minimal level of nutrition and hydration which would, in effect, achieve nothing in terms of sustaining life for a longer period than the present arrangements. In any event, as Dr B points out, the NICE guidelines for patients living with advanced dementia is that tube feeding should not normally be deployed.
28. In his position statement prepared on behalf of the applicant, Mr Lewis succinctly and conveniently summarises Dr B's treatment plan. This would include:
 - a. Administering of Fortisip three times per day, with 750 to 1,000 calories per day, which would still be sub-optimal but not immediately life-threatening;
 - b. Weighing of QJ twice a week;
 - c. Discussing again with QJ, within a week, his present situation and a plan to discharge him back to the nursing home;
 - d. No readmission of QJ to hospital, once discharged back to the care home, if there he refuses to accept food or water.

¹ National Institute of Clinical Excellence, "Decision aid: Enteral (tube) feeding for people living with severe dementia", June 2018.

29. It is unnecessary for me to evaluate ‘best interests’ because I have concluded that QJ should be regarded as capacitous. However it is also right that I acknowledge that QJ, in conjunction with the doctors, has been able to put together a plan which both respects his autonomy and has regard to his dignity. This is an extremely difficult case. I am conscious that it has been the subject of careful consideration and evaluation by all concerned, which has helped me enormously in my own task.