Case No: 12449750

Neutral Citation Number: [2014] EWHC 342 (COP)
IN THE COURT OF PROTECTION

Date: 17 February 2014

Before :

THE HONOURABLE MR JUSTICE PETER JACKSON

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Between :

Heart of England NHS Foundation Trust **Applicant**

-and-

JB (by her litigation friend, the Official Solicitor) **Respondent**

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Vikram Sachdeva (instructed by the NHS Trust) for the Applicant
Michael Horne (instructed by the Official Solicitor) for the Respondent

Hearing dates: 14 and 17 February 2014
Judgment date: 17 February 2014

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JUDGMENT

IMPORTANT NOTICE

This judgment was handed down after a hearing in public. It can be reported provided that the terms of a reporting restriction order made on 14 February 2014 are complied with. The order prevents the identification of JB, her family, the hospital in which she is being treated and the medical and other staff who are treating and caring for her. Failure to comply with that order will be a contempt of court.

Mr Justice Peter Jackson:

1. The right to decide whether or not to consent to medical treatment is one of the most important rights guaranteed by law. Few decisions are as significant as the decision about whether to have major surgery. For the doctors, it can be difficult to know what recommendation to make. For the patient, the decision about whether to accept or reject medical advice involves weighing up the risks and benefits according to the patient's own system of values against a background where diagnosis and prognosis are rarely certain, even for the doctors. Such decisions are intensely personal. They are taken in stressful circumstances. There are no right or wrong answers. The freedom to choose for oneself is a part of what it means to be a human being.

2. For this reason, anyone capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone. In the absence of consent any invasion of the body will be a criminal assault. The fact that the intervention is well-meaning or therapeutic makes no difference.

3. There are some who, as a result of an impairment or disturbance in the functioning of the mind or brain, lack the mental capacity to decide these things for themselves. For their sake, there is a system of legal protection, now codified in the Mental Capacity Act 2005. This empowers the Court of Protection to authorise actions that would be in the best interests of the incapacitated person.

4. The Act contains a number of important general principles regarding capacity:

    - 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: s.2(1).

    - A person must be assumed to have capacity unless it is established that he lacks capacity: s.1(2).

- The question of whether a person lacks capacity must be decided on the balance of probabilities: s.2(4).

- 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: s.1(3)

- A person is not to be treated as unable to make a decision merely because he makes an unwise decision: s.1(4).

- A lack of capacity cannot be established merely by reference to—
  (a) a person's age or appearance, or
  (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity: s.2(3).

5. These principles reflect the self-evident seriousness of interfering with another person's freedom of action. Accordingly, interim measures aside, the power to intervene only arises after it is has been proved that the person concerned lacks capacity. We have no business to be interfering in any other circumstances. This is of particular importance to people with disadvantages or disabilities. The removal of such ability as they have to control their own lives may feel an even greater affront to them that to others who are more fortunate.

6. Furthermore, the Act provides (s.1(6)) that even where a person lacks capacity, any interference with their rights and freedom of action must be the least restrictive possible: this acknowledges that people who lack capacity still have rights and that their freedom of action is as important to them as it is to anyone else.

7. The temptation to base a judgement of a person's capacity upon whether they seem to have made a good or bad decision, and in particular upon whether they have accepted or rejected medical advice, is absolutely to be avoided. That would be to put the cart before the horse or, expressed another way, to allow the tail of welfare to wag the dog of capacity. Any tendency in this direction risks infringing the rights of that group of persons who, though vulnerable, are capable of making their own decisions. Many who suffer from mental illness are well able to make decisions about their medical treatment, and it is important not to make unjustified assumptions to the contrary.

8. These basic considerations are of relevance in the present case. It concerns a 62 year old lady named JB. In earlier life, before she became too unwell, she undertook responsible work. She now lives with her twin sister. She is described by her Community Psychiatric Nurse as a strong willed woman who

before her latest illness was good at needlework and art, enjoyed reading, attended her local church and took a lot of interest in community events.

9. JB has a number of mental and physical disabilities. In her 20s, she was diagnosed as suffering from paranoid schizophrenia for which she has received treatment of various kinds, including during several involuntary hospital admissions, the last being in 2005. Since then she has been subject to what is now known as a Community Treatment Order. She lacks insight into her mental illness but accepts antipsychotic medication to avoid being returned to hospital.

10. JB also has a number of chronic difficulties with her physical health. She suffers from hypertension, poorly controlled insulin-dependent type II diabetes, diabetic retinopathy and anaemia. She is a heavy smoker, which exacerbates peripheral vascular disease by reducing blood flow to her extremities.

11. In May 2013, JB attended a foot clinic with superficial ulcers to both feet. Between the beginning of June and the end of July, she was treated in hospital for an infection in the left foot. While there, she acquired an infection and became seriously unwell. Ultimately, this resolved, as did the condition of her left foot, and she was discharged. However, by August the condition of her right foot had deteriorated to the extent that it had become gangrenous. Medical advice was that it could not be saved and that auto-amputation was the best option. This means that the foot would become mummified and would in time separate itself from the leg by natural processes.

12. JB was again admitted to hospital for most of the month of October for treatment of her right foot. During this time, she was also suspected to have cancer of the bladder. There were discussions about whether she should have an amputation of her right leg to prevent the spread of gangrene and potentially life-threatening infection. JB did not agree to this and doubt was expressed about whether she had capacity to decide. A number of opinions were expressed, some doctors considering that she lacked capacity and others that she was simply making what was seen as an unwise decision. On one particular day, a clinical psychologist who considered the issue in the morning and again in the afternoon reached opposite conclusions. Another consultant psychiatrist, Dr B, was unable to decide either way. Her community psychiatrist, Dr O, reported on 21 October that: *"There is evidence that Chronic Schizophrenia can impact on decision making and other cognitive functions. She is able to understand and retain information regarding proposed treatments however her ability to weigh information appears to be compromised. She has a long-standing pattern of coping with minimisation and historically underplays the concerns raised by clinicians about her health. Currently she reckons that if she continues to dress her foot then healing might occur but was unable to clearly show that she had*

considered the option of possible worsening sepsis and death. She mentioned that she would rather not think about these issues. She also said that everyone would die at some point…"

13. Because of the issue about JB's capacity, a referral to the Court of Protection was considered during this October admission. It transpired that she did not have bladder cancer. She continued to refuse amputation and it was considered that she was well and did not need surgical intervention. At the end of October she was discharged home.

14. On New Year's Eve, JB, having been unwell for several days, was readmitted and has remained in hospital since then. Her right foot was now entirely mummified and by the end of January it had come off, leaving an unresolved wound. Once again, the advice of the surgeons was that an amputation was necessary to allow the wound to be closed and to prevent it becoming infected. JB continued to refuse consent for this on some occasions, though she expressed agreement on others. Indeed, on 4 February she signed a consent form. Once again, doubts were expressed about her capacity, with no clear conclusion being reached. An example is the report of Dr B, who assessed JB on 14 January and concluded that *"I am of the opinion that one needs to be certain of her capacity to consent or refuse the proposed intervention… However one cannot say with certainty she lacks capacity."* It was again agreed that an application would be made to the Court of Protection.

15. In the meantime, discussion was taking place between surgeons, physicians and consultants in rehabilitation as to the nature of the amputation that would be most appropriate. At different times, it has been suggested that there should be amputation below the knee, through the knee or above the knee. Each option has important consequences in relation to the process of rehabilitation and the possibility of the patient walking in future. At the outset of this hearing the Trust's position was that a through-knee operation should be approved, but this then changed to a recommendation for a below-knee operation. It is to be noted that the consent form signed by JB only two days before the proceedings began had covered an above-knee operation. The relevance of all of this is that the attempts to assess her capacity have taken place against a background of shifting medical opinion.

16. On 6 February, the Trust applied to the court for a declaration that JB lacks capacity to make a decision about serious medical treatment. It sought a declaration that it would be in her best interests to have a through-knee amputation and for her to be sedated if she resisted.

17. The Official Solicitor was invited to represent JB, and has agreed to do so, on the basis that she is a person alleged to lack capacity (COP Rules 2007 r.6).

18. Neither JB's twin sister nor her two other siblings have chosen to participate in the proceedings.

19. This hearing has taken place in public over two days, with evidence being taken on the issue of capacity on the first day, the parties making submissions on that issue in writing, and judgment being given on the second day.

20. A reporting restriction order was made on 14 February. It prevents publication of the names and addresses or pictures of JB or her family members, the hospital or the doctors and carers, or any other material likely to lead to the identification of JB. It does not prevent anything else being reported.

21. I turn to the question of whether JB has the capacity to decide whether or not to consent to amputation of her right leg. The Trust says that she does not, relying upon evidence given by Dr O. The Official Solicitor says that she does, relying upon the evidence of Dr Pravin Prabhakaran, consultant psychiatrist, and Mr Jack Collin, consultant surgeon. Each of these witnesses has assessed JB during the past week and gave evidence during the hearing.

Before summarising their evidence, it is convenient to set out the statutory framework that anyone assessing a person's capacity is required to apply. Section 3 of Act provides:

> ***3 Inability to make decisions***
>
> *(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—*
>
> *(a) to understand the information relevant to the decision,*
>
> *(b) to retain that information,*
>
> *(c) to use or weigh that information as part of the process of making the decision, or*
>
> *(d) to communicate his decision (whether by talking, using sign language or any other means).*
>
> *(2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).*
>
> *(3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.*
>
> *(4) The information relevant to a decision includes information about the reasonably foreseeable consequences of—*

(a) deciding one way or another, or

(b) failing to make the decision.

22. The sequence in subsection (1) has its origins in the 1991 Law Commission Consultation Paper No. 129, "Mentally Incapacitated Adults and Decision-Making." This approach was adopted in the influential decision of Thorpe J in *In Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290 at 295. That decision is reminiscent of JB's situation in a number of respects, albeit in a pre-statutory context. It concerned a 68-year-old Broadmoor patient. The headnote continues:

The patient was diagnosed as a chronic paranoid schizophrenic while serving a sentence of imprisonment and was transferred to a secure hospital. He was found to be suffering from an ulcerated foot which became gangrenous and was transferred to a general hospital where a surgeon advised amputation below the knee, failing which his chances of survival were small. He refused consent to that treatment but allowed conservative treatment and his condition improved. However, the hospital refused to give an undertaking that the leg would not be amputated at some future time. He applied for an injunction to prevent amputation without his written consent.

Held, granting the application, that it had not been established that his general capacity was so impaired by his illness as to render him incapable of understanding the nature, purpose and effects of the proposed treatment and so his right of self-determination had not been displaced.

23. Although conclusions cannot be transposed from one case to another, it has to be said that Mr C, who was found to have capacity, exhibited a number of psychiatric features that JB happily lacks. In particular, when explaining his decision not to consent to amputation, Mr C expressed grandiose delusions of an international career in medicine during the course of which he had never lost a patient. He also had a strong conviction that God would not allow him to die. That said, his choice was that he would rather die with two feet than live with one.

24. Returning to the present case, the question is whether JB can understand, retain and use and weigh the relevant information in coming to a decision. As in C's case, what is in my view required is that she should understand the nature, purpose and effects of the proposed treatment, the last of these entailing an understanding of the benefits and risks of deciding to have or not to have one or other of the various kinds of amputation, or of not making a decision at all.

25. What is required here is a broad, general understanding of the kind that is expected from the population at large. JB is not required to understand every last piece of information about her situation and her options: even her doctors would not make that claim. It must also be remembered that

common strategies for dealing with unpalatable dilemmas – for example indecision, avoidance or vacillation – are not to be confused with incapacity. We should not ask more of people whose capacity is questioned than of those whose capacity is undoubted.

26. At all events, it is for the Trust to displace the presumption that JB has capacity on a balance of probabilities. It is important that the right question is asked. When assessing JB in October, Dr O approached matters on the basis that JB was "*unable to clearly show that she had considered the option"* of amputation. Similarly in January, Dr B remarked that *"one needs to be certain of her capacity"* while in February, Dr O recorded that JB *"is unable to fully understand, retain and weigh information…".* These formulations do not sit easily with the burden and standard of proof contained in the Act.

27. A similar issue arises from the statement of Dr W, a vascular surgeon. In common with the other surgeons he believes that an amputation is in JB's best interests. Writing on 5 February, he said *"…we now have a window of opportunity as she has become cooperative with her medical management and has consented to the operation…"* There is a danger that in a difficult case like this the patient is regarded as capable of making a decision that follows medical advice but incapable of making one that does not.

28. At the hearing evidence was taken from Dr O and Dr Prabhakaran via a telephone conference call (so that the latter heard the former's evidence), and from Mr Collin in person.

29. Dr O has been JB's community psychiatrist since October 2013. She has seen her three times: October, January and 12 February. She advises that JB lacks insight into her mental state and does not believe that she has a mental illness. This is not uncommon with schizophrenia. Dr O believes that in relation to her physical health, JB can understand and retain some but not all of what is being said by the doctors, but that her ability to weigh the information is compromised by her tendency to minimise and disbelieve what the doctors are telling her. She conceded that JB's approach was possibly a normal reaction but said that she is not convinced that she had actually weighed all the evidence that she had been given. Nonetheless, over time JB has shown more belief and greater engagement, telling Dr O that she is frightened of surgery.

30. Dr O advises that schizophrenia can have an effect on cognition but she was not in fact able to give any clear instance of irrationality in JB's current thinking. She went so far as to say that the rejection of a through-knee operation was evidence of incapacity, although by the time she gave evidence this had been dropped as a plan.

31. I note that as recently as 16 January, Dr O and Dr B expressed themselves unable to reach a conclusion as to whether JB had capacity and that during

her assessment on 12 February, Dr O obtained only limited co-operation from JB.

32. Dr Prabhakaran assessed JB on 9 and 12 February. She was more communicative with him than with Dr O, possibly because she regarded him as someone who is not implicated in her Community Treatment Order. He confirms the diagnosis of schizophrenia and the absence of any psychotic features or depression. He says that he had a detailed discussion with her about the various forms of amputation. JB was able to understand the main benefits and risks associated with each procedure, including the risk of death. He found her consistent in her views and reasoning process. She was very well orientated and had no problem with understanding or retaining information.

33. Dr Prabhakaran discussed the then proposed through-knee operation, saying that it was the doctors' preferred option. JB replied: *"It is not my preferred option… I have a horror of the whole thing".* She said that she wanted her leg to remain as long as possible and only wanted any necrotic part removed. If she was to have an operation she wanted a longer leg and a hope of walking. She does not want to live her life with a shorter leg.

34. During this conversation, JB would often pause for a long time before answering. Dr Prabhakaran considered this an effect of her schizophrenia impacting on her cognitive functioning, possibly alongside tiredness and the hospital environment. He says that given time, she can process and communicate her clear wishes. He is confident that JB has capacity to make a decision with regard to surgery, including a decision not to have it.

35. Mr Collin assessed JB from a surgical perspective on 13 February. His conversation with her gave him a full opportunity to assess her understanding, as would be normal in such a case. His report details a full conversation. JB was able to give him a lucid and coherent medical history. In Mr Collin's experience, few patients would give a better account. She has a tendency to minimise, but this is a natural response and not evidence of any incapacity. Mr Collin is aware that JB is mentally ill but throughout the discussion she gave him no reason to suspect a lack of capacity to consent or withhold consent for any essential operation.

36. Mr Collin explained that JB's decision in October to refuse surgery was unusual but not illogical and that from the medical perspective the loss of the foot by natural processes had been satisfactory. Surgically, her position is better now than it had been in October in that she is not currently suffering from any infection. As matters now stand, it is Mr Collin's opinion that a below-knee amputation is the only sensible clinical decision to make, but if JB does not want this there would be no compelling reason to seek to persuade her otherwise. A substantial risk of infection with possibly life-threatening consequences in the longer term undoubtedly exists and the medical advice

from any surgeon in the land would be clear, but she does not have to take it. Apart from anything else, the greater short-term risks arise from remaining in hospital with the risk of infection and from the small but not insignificant possibility of a major adverse consequence from surgery of this kind.

37. It was, perhaps surprisingly, suggested to Mr Collin that he lacked the expertise to assess capacity. He accepted that the assessment of mental illness was outside his remit but said that he was well qualified to assess the capacity of patients to consent to operations. I agree. All doctors and many non-medical professionals (for example, social workers and solicitors) have to assess capacity at one time or another. Bearing in mind JB's longstanding mental illness it is entirely appropriate that the core assessment of her capacity comes from psychiatrists, but other disciplines also have an important contribution to make.

38. The combined and complementary evidence of Dr Prabhakaran and Mr Collin provides powerful confirmation that JB has the ability to understand, retain and weigh and use the necessary information about the nature, purpose and effects of the proposed treatment. I accept the view of Dr Prabhakaran that JB's schizophrenia is relevant to the way in which she decides, and not to her capacity to decide. Her tendency at times to be uncommunicative or avoidant and to minimise the risks of inaction are understandable human ways of dealing with her predicament and do not amount to incapacity.

39. I depart from the assessment of Dr O because I am not satisfied that she establishes the necessary link between JB's mental illness and the alleged incapacity. Further, her analysis demands more of JB than the law requires. It is not for JB to understand everything, or to prove anything. Dr O among others has perfectly properly raised questions about JB's capacity, but her evidence does no more than that and does not discharge the burden upon the Trust.

40. I do not accept the Trust's submission that incapacity can be deduced from isolated instances of eccentric reasoning on the part of JB: for example, agreeing to intravenous antibiotics or blood transfusion but refusing the necessary cannulation. I also reject the submission that those who conclude that JB does not lack capacity have failed to grapple with the facts that (i) she undoubtedly lacks capacity in relation to treatment for her mental illness and (ii) she has lacked capacity in relation to surgical treatment in the past and (iii) she has changed her position from refusal of all surgery to a willingness to contemplate an operation of some kind, a situation calling for investigation. As to the first element, as has already been said, there is no necessary correlation between a lack of insight into schizophrenia and incapacity to decide about surgery. The second element begs the question, in that it has not been established that JB has ever lacked capacity to decide about surgery. Finally, the development in JB's thinking about amputation was in my view well understood by Dr Prahakaran. Insofar as it calls for any

explanation, her view has evolved over time in a way that is consistent with her mental state.

41. Nor do I accept the Official Solicitor's submission that the issue is whether JB has the capacity to consent to a below-knee amputation as opposed to operations no longer proposed by the Trust, i.e. through-knee or above-knee amputations. As explained above, what is required is an understanding of the nature, purpose and effects of the proposed treatment. In this sense 'the proposed treatment' is surgical treatment for a potentially gangrenous limb, and is not limited to one of the possible operations. Treating each type of amputation as different is an impractical and unnecessary distinction that would diminish the scope of JB's capacity and potentially lead to unprofitable reassessments with every change in the treatment programme.

42. My conclusion is that JB undoubtedly has a disturbance in the functioning of her mind in the form of paranoid schizophrenia (as to which she lacks insight), but that it has not been established that she thereby lacks the capacity to make a decision about surgery for herself. On the contrary, the evidence establishes that she does have capacity to decide whether to undergo an amputation of whatever kind. She now appears to be open to having the below-knee operation that the doctors recommend. Whether she has it will be a matter for her to decide for herself with the support of those around her.

43. On that basis, these proceedings are concluded.