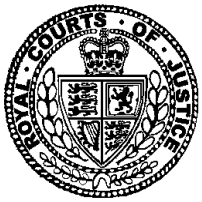

Neutral Citation Number: [2024] EWCA Civ 896

Case No: CA-2023-001892

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE COURT OF PROTECTION
Mrs Justice Roberts
COP 1405715T

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 31/07/2024

Before:

LADY JUSTICE KING
LORD JUSTICE SINGH
and
LORD JUSTICE BAKER

- -

Between:

(1) THIRUMALESH CHELLAMAL HEMACHANDRAN **(2) REVATHI MALESH THIRUMALESH**	**Defendants/ Appellants**
- and –	
(1) SUDIKSHA THIRUMALESH (DEC'D) **(By her litigation friend, The Official Solicitor)** **(2) UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST**	**Claimants/ Respondents**
- and –	
MIND	**Intervener**

- -
- -

Bruno Quintavalle (instructed by **Andrew Storch Solicitors**) for the **Appellants**
Katie Gollop KC and Olivia Kirkbride (instructed by the **Official Solicitor**) for the **First Respondent**
Vikram Sachdeva KC, Catherine Dobson and Isabella Buono (instructed by **Bevan Brittan LLP)** for the **Second Respondent**
Alex Ruck Keene KC (Hons) and Neil Allen (instructed by **MIND**) for the **Intervener**

Hearing dates: 2-3 May 2024

- -

Approved Judgment

This judgment was handed down remotely at 11.00am on 31 July 2024 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

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Lady Justice King:

Introduction

1. Sudiksha Thirumalesh ("Sudiksha") died on 12 September 2023. She was 19 years old. She was born with a rare mitochondrial disorder known as Mitochondrial Depletion Syndrome RRM2B ("RRM2B"), a chronic degenerative disease with no known cure.

2. On 20 July 2023, University Hospitals Birmingham NHS Foundation Trust ("the Trust") made an emergency application to the Court of Protection asking the court to approve a palliative care plan for Sudiksha and for her life sustaining treatment to be withdrawn.

3. The issue which came before the late Roberts J ("the judge"), namely Sudiksha's capacity to make decisions in relation to her medical treatment, was both unusual and difficult and is central to this appeal. Whilst the medical evidence was overwhelming that Sudiksha was in multi-organ failure and nearing the end of her life, she was fully conscious and able to communicate through a voice box. She was adamant that she wished to have the opportunity to be considered for experimental nucleoside treatment in America or Canada. She wanted to *"die trying to live".*

4. On 7 August 2023, the judge made a declaration that Sudiksha lacked capacity "to give or withhold her agreement to medical treatment including palliative treatment".

5. The court having decided that Sudiksha lacked capacity to make decisions about her medical care, the case was listed to be heard on 23 October 2023 with a time estimate of two days in order for the court to "determine [Sudiksha's] best interests in terms of medical treatment".

6. In the event, no best interests decision was ever made by a court as Sudiksha died only 35 days after the declaration was made. Her end-of-life care was provided under the terms of a treatment plan ("the treatment plan") without any judicial intervention. The plan had been agreed with Thirumalesh Chellamal Hemachandran and Revathi Malesh Thirumalesh ("the parents") some months previously in May 2023.

7. On 5 October 2023, Sudiksha's parents (who had been the 2nd and 3rd Respondents in the Court of Protection proceedings) issued an Appellant's Notice seeking permission to appeal against the declaration of incapacity. Notwithstanding that Sudiksha's death meant that the appeal was academic, I granted permission to appeal and in due course, also permission for MIND to intervene.

8. Mr Bruno Quintavalle represented the parents, Katie Gollop KC and Olivia Kirkbride represented the Official Solicitor, Vikram Sachdeva KC, Catherine Dobson, and Isabella Buono represented the Trust and Alex Ruck Keene KC and Neil Allen represented MIND.

9. Having heard extensive submissions from the parties and from MIND, I would allow the appeal. It follows that the declaration made by the judge on 7 August 2023 that Sudiksha lacked the capacity to give or withhold her agreement to medical treatment, including palliative treatment, will therefore be set aside. That being the case, the presumption of capacity contained in section 1(2) Mental Capacity Act 2005 ("MCA")

means that Sudiksha is presumed to have had the capacity to give or withhold her agreement to medical treatment, including palliative treatment, at all times leading up to her death.

10. In reaching that decision, I should be clear that I make no criticism of the judge who demonstrated the same care and compassion in this case as she did in every case she heard during her time as a High Court Judge before her untimely death. The decision she reached was in part, at least, influenced by an established legal approach to the relevance of a patient's belief in their illness and prognosis. That approach is, for the reasons set out in this judgment, wrong and contrary to Court of Appeal authority.

Background

11. All who came into contact with Sudiksha agree that she was a remarkable young woman: hardworking, determined, and resilient. Supported by her parents and brother, she had managed to attend a mainstream school where she was studying for A levels. She did this notwithstanding her significant and deteriorating health problems which included: impaired sight, hearing loss, muscle weakness, bone disease, gut dysmotility issues, end stage renal failure, and lung damage.

12. On 1 August 2022, Sudiksha was admitted to the Intensive Care Unit ("ICU") at the Queen Elizabeth Hospital in Birmingham with community-acquired pneumonia and Covid which had led to respiratory arrest.

13. On her admission to the ICU, the treating clinicians were unable to extubate Sudiksha and as a consequence, she remained on mechanical ventilation via tracheostomy, fed by PEG and with dialysis every alternate day until the end of her life.

14. By 31 March 2023, the Trust's multi-disciplinary team were recommending that Sudiksha should be moved to a palliative care treatment plan, and in particular that there should be a limit on the dialysis Sudiksha was receiving for her kidney failure. Dr William Tunnicliffe, the consultant in critical care and respiratory medicine at the Trust, explained in his first statement that the dialysis was "unpleasant, distressing and increasingly impossible to maintain given her reduced blood pressure which gave rise to a risk of cardiac arrest during the dialysis process". By this time there was no longer any prospect of the kidney transplant which had been hoped for prior to Sudiksha's admission to hospital.

15. On 12 April 2023, the Trust made an application seeking permission to perform a capacity assessment on Sudiksha which was opposed by her parents. The following day the judge made an interim declaration that there was "reason to believe that Sudiksha lacks capacity to conduct these proceedings". The Official Solicitor was appointed to represent Sudiksha.

16. On 18 April 2023, Dr Bagchi, a consultant psychiatrist, filed a report expressing his view that Sudiksha had full capacity. On 20 April 2023, Francis J granted permission for a second psychiatrist, Dr Mynors-Wallis, to consider the issue of capacity. Sudiksha refused to speak to Dr Mynors-Wallis and so he filed his first report shortly afterwards on 26 April 2023. Relying on research relating to the impact of lengthy stays in ICU and taking into account Sudiksha's age, he concluded that she lacked capacity.

17. Importantly, on 15 May 2023, Judd J approved a treatment plan which reflected many of Sudiksha's stated preferences. The plan was agreed by the parties, including the parents, without the need for a hearing and remained the operative plan until Sudiksha's death.

18. On 14 July and again four days later on 18 July 2023, Sudiksha went into respiratory arrest and had to receive lifesaving treatment. In the light of this further significant deterioration, the Trust made an emergency application on 20 July 2023 to approve a palliative care plan and for her life-sustaining treatment to be removed.

19. On 25 July 2023, in circumstances which have not been explored, David Foster, a solicitor of Moore Barlow LLP ("Moore Barlow"), visited Sudiksha and prepared a note of his meeting which was served on the parties. Mr Foster attended the subsequent directions hearing in front of Peel J with leading and junior counsel purporting to represent Sudiksha and seeking the discharge of the Official Solicitor as litigation friend for Sudiksha.

20. Peel J permitted Moore Barlow to participate fully despite not representing a party, as did the judge when the hearing of the issue of capacity came on as urgent vacation business on 7 August 2023. Peel J declined to discharge the Official Solicitor.

21. An order was made for Dr Mynors-Wallis to prepare a further report. This he did, this time having seen Sudiksha and her parents. He filed a second report on 5 August 2023 in which he explained that, now having had the opportunity to assess Sudiksha, he had revised his opinion and was now of the view that she had capacity to make decisions in relation to her medical treatment.

22. At the hearing to determine the issue of capacity on 7 August 2023, Dr Bagchi and Dr Mynors-Wallis, the Official Solicitor, and Moore Barlow all expressed their opinion that Sudiksha had capacity. The Trust alone maintained that she did not; their case was that she was delusional and therefore unable to make a decision as to her medical treatment.

Sudiksha's desire to receive experimental Nucleoside Therapy

23. By early October 2022, Professor Robert McFarland, an independent consultant paediatric neurologist, considered Sudiksha to be in the terminal stages of her illness. Professor McFarland is a world leading expert on RRM2B specialising in the pathogenicity in mitochondrial disease and its management. On 5 October 2022, the family had a meeting with Professor McFarland at which he explained that all possible treatments had been given and that Sudiksha was entering the last part of her life.

24. Sudiksha's parents were unable to accept that she was dying, and both they and Sudiksha believed that she was suffering from the effects of Long Covid and that she would recover enough to have a kidney transplant. Her parents were anxious to explore any options which would save her life and in particular, the possibility of Sudiksha going abroad to receive experimental nucleoside treatment which would involve taking modified nucleoside molecules in an attempt to increase the production of healthy mitochondrial DNA.

25. On 11 April 2023, Professor McFarland explained in a report in the form of an email, that Sudiksha had an extremely rare (fewer than 100 cases reported worldwide) form of mitochondrial disease for which there is no cure. The report explained that nucleoside therapy of the type that the family hoped to access for Sudiksha had been mooted as a potential treatment, and that patients with a related condition called TK2 deficiency appeared to have had some benefit if it was given early in the course of the disease. Professor McFarland explained that the quantities and ratio of bases required to synthesise mitochondrial DNA ("mtDNA"), which would be necessary in order to attempt to treat Sudiksha*'s* RRM2B related mitochondrial disease (as opposed to TK2), had not been determined and any progress had been further hampered by the lack of an appropriate animal model of disease. Both Professor McFarland's team and other research teams worldwide, he said, remained "some distance" from being able to provide treatment for RRM2B.

26. Professor McFarland concluded that Sudiksha's prognosis was "extremely bleak" and that she had now entered the terminal phase of her illness. In his opinion, "the kindest and most clinically responsible course of action would now be to de-escalate the intensive care and make Sudiksha comfortable."

27. Meanwhile, the family had been exploring three options in relation to such experimental nucleoside therapy. As the father had put it in a statement for the court proceedings, as Professor McFarland did not "deliver" such treatment "[i]t is appropriate, particularly given Sudiksha's passion for life, to pursue all possible options however remote the current Trust (who are overly pessimistic) might think they are." Contact was made with Dr Hirano at New York Presbyterian Hospital, Dr Kenneth Myers at McGill Hospital and the Children of Philadelphia Hospital.

28. On 30 June 2022, Hayden J made an order which recorded agreed directions by which, amongst other things, the Trust agreed to liaise with Dr Hirano in relation to the availability of nucleoside treatment.

29. As is clear from the terms of Hayden J's order, this was not a case where the clinicians felt unable to assist the family in their search for help elsewhere in the world. The unequivocal view of the clinicians, informed by Professor McFarland's expertise, was that even had nucleoside therapy been at a stage in its experimental development that Sudiksha could be treated with it, her illness had progressed too far for her to have been able to benefit from it. Notwithstanding that view, Dr Tunnicliffe wrote a lengthy email to Dr Hirano in New York putting a number of questions to him which the family had asked him to ask, including whether the unit would be willing to treat Sudiksha and whether Dr Hirano could recommend any other therapy. In addition, contact was made with the other two hospitals which had been identified by the family.

Capacity to Decide on Medical Treatment

30. This appeal relates only to Sudiksha's capacity to decide on medical treatment. It is not concerned with her capacity to litigate. Further, whilst each of the experts were of the view that Sudiksha was a vulnerable adult and therefore a decision as to whether a move to palliative care was in her best interests could potentially have been made under the inherent jurisdiction, that difficult issue was not before the court.

31. It is well established that any decision that a person lacks capacity is determined against the background of the principles set out in section 1 MCA which for the purposes of this appeal, include what are often referred to as the presumption of capacity and the principle of autonomy:

> "The principles
>
> (1) The following principles apply for the purposes of this Act.
>
> (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
>
> (3) 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.
>
> (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
>
> (5) 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.
>
> (6) 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."

32. The decisions in this case related to Sudiksha, who, notwithstanding her terrible illness, was studying for A levels before contracting Covid which led to her long-term admission to ICU. She was a 19-year-old young woman who was fully conscious, was not suffering from any mental illness or brain damage and was communicating freely with both her family and the medical team caring for her. Whilst distressed on occasion, it was in the context of specific treatment. She was clear at all times in expressing her wishes, namely that she wanted to be provided with all active care possible, to try experimental treatment and to *"die trying to live".*

33. In order to anchor the principle of autonomy, which must be at the forefront of any consideration of Sudiksha's case, I can do no better than adopt the introduction of MacDonald J in *Kings College Hospital v C & V* [2015] EWCOP 80 *("Kings College")*:

> "1. A capacitous individual is entitled to decide whether or not to accept medical treatment. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient. In *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 102 Lord Donaldson observed that:
>
> > "An adult patient who…suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered… This right of choice is not

> limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."
>
> 2. This position reflects the value that society places on personal autonomy in matters of medical treatment and the very long established right of the patient to choose to accept or refuse medical treatment from his or her doctor (voluntas aegroti suprema lex). Over his or her own body and mind, the individual is sovereign (John Stuart Mill, On Liberty, 1859)".

34. Given the myriad of influences in any person's background and life and perhaps particularly in relation to a young adult, it is essential always for any person conducting a capacity assessment to have in mind the terms of section 1(4) MCA: "[a] person is not to be treated as unable to make a decision merely because he makes an unwise decision."

35. In *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP), Peter Jackson J (as he then was) put it this way:

> "7. The temptation to base a judgment of a person's capacity upon whether they seem to have made a good or bad decision, and in particular on 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."

36. This later principle is further reflected in section 2(3)(a) and (b) MCA which say that a lack of capacity cannot be established "merely by reference to" a person's age or appearance or a condition of his or aspect of his behaviour which might "lead others to make unjustified assumptions about his capacity."

37. In *WBC Local Authority v Z* [2016] EWCOP 4, Cobb J discussed young people in the context of risk-taking saying that: "[r]isk-taking is often unwise. It is also an inherent, inevitable and perhaps necessary part of adolescence and early adulthood experience." At [67], Cobb J stressed the importance of separating out, as far as possible, this type of risk-taking from that which "reveals or may reveal" a lack of capacity. In *PC and NC v City of York Council* ("*PC and NC*") [2013] EWCA Civ 478; [2014] Fam 10, McFarlane LJ (as he then was) spoke of the importance of respecting:

> "[53] … the space between an unwise decision and one which an individual does not have capacity to take … for it is within that space that an individual's autonomy operates."

38. Moving on from the guiding principles, section 2(1) MCA provides:

> "(1) 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 disturbance in the functioning of, the mind or brain." (*My emphasis*)

39. Critical therefore is for a person making an assessment of capacity to conclude that the person is unable to make a decision for him or herself and that that inability is because of an "impairment of, or disturbance in the functioning of, the mind or brain", hereafter referred to as "an impairment of mind".

40. This part of the test for capacity is most commonly known as the "diagnostic test". Alex Ruck Keene KC and Neil Allen, acting for MIND as an intervener in the appeal, submitted that a more appropriate term would be to refer to the "impairment test" rather than the diagnostic test given that, in his submission, no diagnosis of mental illness is required in order to satisfy the test (see *North Bristol NHS Trust v R* [2023] EWCOP 5 ("*North Bristol*") at [47]-[48]). As what is required is that the inability to make a decision is "*because of"* an impairment of mind, it follows that a delusional belief on Sudiksha's part would amount to an impairment of mind. A decision, however, which to many older and/or more experienced people would seem to be thoroughly unwise, would not, without more, amount to such an impairment.

41. It is therefore necessary to determine whether a person is unable to make a decision about a matter for the purposes of section 2 MCA. This is governed by the section 3 MCA "functional test" which provides that:

> "(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)."

42. In *A Local Authority v JB* [2021] UKSC 52; [2022] AC 1322 *("JB")*, the Supreme Court considered the proper approach for [or to] determining capacity. Lord Stephens, with whom Lord Briggs, Lady Arden, Lord Burrows and Lady Rose JJSC agreed, set out at [56] onwards the general approach to be adopted in relation to an assessment of capacity. He emphasised at [65] that section 2(1) is a single test "albeit that it falls to be interpreted by applying the more detailed description given around it in sections 2 and 3".

43. Lord Stephens went on at [66] to say that section 2(1) MCA requires the court to address two questions which, he says at [79] are to be approached in the following sequence:

    i) Whether P is unable to make a decision for himself in relation to the matter [65]-[77] (section 3: the functional test).

ii) Whether that inability to make a decision is "because of" an impairment of, or disturbance in the functioning of, the mind or brain (section 2(1): the diagnostic or the mental impairment test):

> "78. The second question looks to whether there is a clear causative nexus between P's inability to make a decision for himself in relation to the matter and an impairment of, or a disturbance in the functioning of, P's mind or brain."

44. In relation to the first question, the functional test, Lord Stephens said at [68] that as the assessment of capacity is decision specific, "the court is required to identify the correct formulation of "the matter" in respect of which it must evaluate whether P is unable to make a decision for himself." He went on at [69]:

> "The correct formulation of "the matter" then leads to a requirement to identify "the information relevant to the decision" under section 3(1)(a) which includes information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision: see section 3(4)."

45. Lord Stephens said at [76] that, once the information relevant to the decision had been identified, then: "P is unable to make a decision for himself in relation to the matter (section 2(1)) if, for instance, he is unable to understand the information (section 3(1)(a)) or to use or weigh that information as part of the process of making the decision (section 3(1)(c))." It should be noted that whilst reference is made to the statutory requirement to understand the information, no reference is made by the Supreme Court to it being a necessary ingredient for P to <u>believe</u> the relevant information in order for him or her to be regarded as having understood it or to be able to use or weigh it. Lord Stephens relies simply on the words of the statute for his analysis.

46. In *Kings College*, MacDonald J said this in relation to a person's ability to use and weigh information:

> "38. It is important to note that s3(1)(c) is engaged where a person is *unable* to use and weigh the relevant information as part of the process of making the decision. What is required is that the person is able to employ the relevant information in the decision making process and determine what weight to give it relative to other information required to make the decision. Where a court is satisfied that a person is able to use and weigh the relevant information, the weight to be attached to that information in the decision making process is a matter for the decision maker. …If P is unable to make the decision his or herself in relation to the matter then the court moves to the second question namely whether the inability is "because of" an impairment of, or a disturbance in the functioning of, P's mind or brain."

47. In order to satisfy the functional test, Sudiksha needed to be able to understand that nucleoside treatment, even if available, would not help her and that the reasonably

foreseeable consequences of her refusing to move to palliative care was the likelihood that her inevitable and reasonably imminent death, would be painful and unregulated.

The role of '*Belief*' *in the functional test*

48. The Trust's position in writing was that "where there was an objectively verifiable medical consensus as to the consequences of having, or not having, treatment, a person must believe, or accept as true, the information which informs the matter in order to understand it for the purposes of section 3(1) MCA". Mr Sachdeva argued that the requirement of belief was not an attempt to add a gloss to the statute, but rather that it followed from the ordinary reading of the requirement of section 3(1) MCA that a person must understand information relevant to a decision about medical treatment. Relevant information, he submitted, includes information as to the consequences of having or not having medical treatment. If a person does not believe relevant information that is objectively true, then the person will proceed on the basis of incorrect information and will, under section 3(1)(a) be unable to make a decision for him or herself.

49. The insertion of 'belief', referred to by Mr Sachdeva as a necessary feature of understanding for the purposes of section 3(1)(a) MCA, finds its genesis in the pre-MCA High Court case of *In re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, where Thorpe J said at page 295:

> "I consider helpful Dr Eastman's analysis of the decision-making process into three stages: first, comprehending and retaining treatment information, secondly, believing it and, thirdly, weighing it in the balance to arrive at choice."

50. Next in time, the Court of Appeal considered the issue in *Re MB (Medical Treatment)* [1997] 2 FLR 426. Butler-Sloss LJ at page 437 explained the test as follows:

> "A person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment. That inability to make a decision will occur when:
>
> (a) the patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
>
> (b) the patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision. If, as Thorpe J observed in *Re C* … , a compulsive disorder or phobia from which the patient suffers stifles belief in the information presented to her, *then the decision may not be a true one.* As Lord Cockburn CJ put it in *Banks v Goodfellow* (1870) LR 5 QB 549, 569:

> '… one object may be so forced upon the attention of the invalid as to shut out all others that might require consideration.'" *(my emphasis)*

51. Put in post-MCA terms, Butler-Sloss LJ in this well-known passage was saying that where an impairment of mind prevents belief in information relevant to a decision, then the decision *may* not be capacitous. Unfortunately and somewhat confusingly, the adoption by Butler-Sloss LJ in the citation above at (b) of what Thorpe J was purported to have said in *Re C ("… a compulsive disorder or phobia from which the patient suffers stifles belief in the information presented to her, then the decision may not be a true one"*) would appear to be an incorrect reference, as no such quotation can be found in the report of *Re C* itself. Notwithstanding the endeavours of Miss Gollop on behalf of the Official Solicitor, the source of the reference has not been identified. In my view, notwithstanding this "wrinkle", it is quite clear that Butler-Sloss LJ was saying that a failure to believe information *may* render a person unable to make a decision for the purposes of section 3(i)(a) and not that it inevitably *will* have such a consequence.

52. The Trust's position, as outlined above, relied on the observations made by Munby J (as he then was) ten years after *Re MB* in the third and most recent case directly on the subject, this time in the High Court in the case of *Local Authority X v MM* [2007] EWHC 2003 (Fam); [2009] 1 FLR 443 (*"Re MM")* (which was handed down on 21 August 2007 and therefore before the MCA which came in force on 1 October 2007). Before setting out in full Butler-Sloss LJ's test (set out a [50] above), Munby J said:

> "67. What is also clear, and again I need not cite authority in support, is that the general rule of English law, whatever the context, is that the test of capacity is the ability (whether or not one chooses to exercise it) to understand the nature and quality of the relevant transaction.
>
> 68. That puts the point at a very general level of abstraction. A more focussed test is to be found in *Re MB (Medical Treatment)* [1997] 2 FLR 426. But first I must go back to *In re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, where Thorpe J said this at page 295:
>
> > "I consider helpful Dr Eastman's analysis of the decision-making process into three stages: first, comprehending and retaining treatment information, secondly, believing it and, thirdly, weighing it in the balance to arrive at choice."
>
> 69. That was a case involving the question of capacity to consent to medical treatment. So too was *Re MB (Medical Treatment)* [1997] 2 FLR 426, where Butler-Sloss LJ at page 437 explained the test as follows……"

53. At [80] Munby J said that in his view there is no relevant distinction between the test as formulated in *Re MB* and the test set out in section 3(1) of the MCA. He said that

"the one merely encapsulates in the language of the Parliamentary draftsmen the principles hitherto expounded by the judges in the other". He went on:

> "81. Before I leave *Re MB* and section 3(1) of the Act, there is one other point to be made. It will have been noticed that in *Re C* Thorpe J identified, as the second of three ingredients of the test, the ability or capacity to "believe" the relevant information, whereas that ingredient is seemingly missing both from the formulation of the test in *Re MB* and from section 3(1) of the Act. The answer to this seeming lack of correspondence between the tests in *Re C* and *Re MB* was provided by Mr Joseph O'Brien on behalf of KM. It is to be found towards the end of the passage which I quoted above from Butler-Sloss LJ's judgment in *Re MB*. If one does not "believe" a particular piece of information then one does not, in truth, "comprehend" or "understand" it, nor can it be said that one is able to "use" or "weigh" it. *In other words, the specific requirement of belief is subsumed in the more general requirements of understanding and of ability to use and weigh information." (my emphasis)*

Munby J concluded:

> "To summarise: i) *Re MB (Medical Treatment)* [1997] 2 FLR 426 sets out the test where the question is whether someone has capacity to consent to medical treatment."

54. With all the respect inevitably and properly given to Munby J (as he then was), the "lack of correspondence" between Thorpe J's test as set out in *Re C* and that of Butler-Sloss LJ in *Re MB* is that, in *Re C,* belief is stated to be a requirement, whereas, in *Re MB*, although a lack of belief may undermine a decision, it is not an absolute requirement. For my part I am unable to see anything in Butler-Sloss LJ's judgment which could be taken to be saying, as Munby J suggested, that "[i]f one does not "believe" a particular piece of information then one does not, in truth, "comprehend" or "understand" it, nor can it be said that one is able to "use" or "weigh" it."

55. The Court has been told that, as a consequence of Munby J's conclusion in *Re MM* that without belief there can be no understanding or ability to use or weigh up information, there has grown up what is often as Munby J called it "the *Re MB* test", and that courts have proceeded on the basis that in order to 'understand' information for the purposes of section 3(1)(a) MCA, the patient concerned must believe that information. Miss Gollop, by way of example, took the court to two first instance cases: *Leicester City Council v MPZ* [2019] EWCOP 64 *("Re MPZ")* where the judge said at [34] that "[t]he case law makes it clear that a failure to believe is a failure to understand and use or weigh" and *Re BNK (Dental Treatment)* [2023] EWCOP 56 where at [9] the judge said that "P will also be deprived of capacity if he does not believe the treatment information, as 'belief' is subsumed in the more general requirements of understanding and of ability to use and weigh information: Munby J in *A Local Authority v MM* … [81]".

56. *An NHS Trust v XB, YB & ZB* [2021] COPLR 505 was a case which on its facts was very different from the one with which this court is concerned. Whilst Theis J did not refer to either *Re MM* or to *Re MB* in her judgment, it provides an example of where a

lack of belief was critical to the determination of capacity. In that case the patient suffered from a severe form of schizophrenia. One of the effects of his condition was that he did not believe he had life threatening levels of hypertension, but rather believed that the essential medication necessary to control his blood pressure, was being used as a means to damage or control him. In reaching the inevitable conclusion that the patient lacked capacity Theis J said:

> "61. Second, XB lacks the capacity to make the decision about the need to take the antihypertensive medication. XB understands what hypertension is and the serious consequences if left untreated. However, he continues to refuse treatment because he does not believe that he suffers from hypertension. He considers staff are lying to him about his diagnosis in order to damage or control him. As a result of his mental ill health he is unable to use or weigh up the information about the benefits and risks of taking or not taking the medication, as he does not believe he suffers from the condition being treated."

57. During the course of submissions, Mr Sachdeva, having heard the submissions of the other parties and in discussions with the Court as they looked together with him at *Re C* and at the use of the word *may* by Butler-Sloss LJ in *Re MB,* refined his submissions, so that his final position on behalf of the Trust was that:

> "Where there is objectively verifiable medical consensus as to the consequences of not having medical treatment, if a person does not believe or accept that information to be true, it *may be* that they are unable to understand it and/or unable to weigh it for the purposes of the MCA."

58. This approach dovetails with that of both the Official Solicitor and of MIND (Mr Quintavalle on behalf of the appellants, chose not to concentrate to any extent on this aspect of their grounds of appeal). The Official Solicitor submitted that a person who does not believe relevant information, whether it be factual or opinion, may lack capacity, but equally they may not. The meaning of each of the words "understand", "use" and "weigh" is, she submits, different from the meaning of the word "believe." The statutory language Miss Gollop submits is complete in meaning: there is no missing meaning, and no implicit or subsumed meaning that needs to be made explicit and no addition or embellishment is required. I agree.

59. As McFarlane LJ said in *PC and NC*:

> "37. The central provisions of the MCA 2005 have been widely welcomed as an example of plain and clear statutory language. I would therefore deprecate any attempt to add any embellishment or gloss to the statutory wording unless to do so is plainly necessary."

60. Nothing in the recent approach of the Supreme Court would appear to indicate anything to the contrary.

61. It follows that in relation to the judgment with which I am concerned, in order to understand and/or to use and weigh up the relevant information, Sudiksha's belief as to her prognosis and the likelihood of her receiving effective nucleoside treatment was relevant, but not determinative as to whether she was able to make a decision under section 3 and therefore satisfy the functional test.

The Psychiatric Evidence and Clinical Evidence

62. The judge had the benefit of oral evidence from both psychiatrists and from Dr Tunnicliffe in order to inform her decision as to whether Sudiksha was able to make a decision (the functional part of the test) and if not, whether that inability was *because of* an impairment of mind (the mental impairment part of the test).

63. The judge's conclusion that Sudiksha lacked capacity turned almost entirely on her having adopted Dr Mynors-Wallis' analysis in his first report of 26 April 2023 provided at a time when he had not seen Sudiksha. It follows, by implication, that she had rejected his second report of 5 August 2023 when, having seen and assessed Sudiksha, he had revised his conclusion and his expert opinion was that she had capacity. It is therefore necessary to consider the reports and evidence of both Dr Bagchi and Dr Mynors-Wallis in a little detail.

Dr Bagchi:

64. Dr Dhruba Bagchi is a Consultant Psychiatrist in the Department of Liaison Psychiatry at the Trust. His role was by way of being the "in house" psychiatrist who would be asked to see and treat Sudiksha had the clinicians had concerns about her mental health. That had not been necessary. He was asked to see Sudiksha in order to give his views as to whether she had capacity so as to decide on the medical treatment plan proposed by the Trust including life-sustaining treatment. Dr Bagchi saw Sudiksha on 14 April 2023 in the company of Ms Yvonne Chapman, the solicitor instructed as an agent of the Official Solicitor to meet with Sudiksha.

65. Dr Bagchi found Sudiksha to be alert and clear in consciousness, she articulated clearly and did not get too emotional, although she did get agitated when Dr Bagchi attempted to talk about her wishes in the event that her condition deteriorated. She said that she wanted treatment, speaking of possible treatment in America and said that she did not trust the doctors.

66. Sudiksha knew her prognosis was poor, but said that she did not agree with the doctors when they told her that she would die. Dr Bagchi was unable to explain end-of-life care to Sudiksha as "she simply [would] not accept that this was the case."

67. Dr Bagchi concluded that there was no evidence of impairment or disturbance of functioning of mind or brain and that her view that "I don't trust them when they say I am going to die" was not delusional.

68. Dr Bagchi saw Sudiksha again on 11 May 2023. She was alert and once again said that she wanted active treatment. Dr Bagchi found her to be "open to discussion and reflective and capable of listening, absorbing information given and [able to] form her opinion".

69. Dr Bagchi at the request of the family, saw Sudiksha again on four occasions on 1, 2, 3, and 4 August 2023. Sudiksha was in Dr Bagchi's opinion, able to express her views describing herself as being "strong in mind" and as having "a positive attitude".

70. Sudiksha told Dr Bagchi that she understood that her condition was progressive, but that she did not think that she was dying and did not want to be put on the palliative pathway. She told him that she would like to try and get the new treatment for her condition in Canada. She had, she said, a different view from the doctors about palliative care, and she wanted any emergent complications to be treated. Sudiksha told Dr Bagchi that *"I want to die trying to live. We have to try everything".*

71. Dr Bagchi in his written report, whilst not applying the test as set out in the Mental Capacity Act, concluded that Sudiksha was able to express her wishes clearly and consistently, that she understood information given to her and that she was able to come to her own conclusion and to communicate clearly.

72. Dr Bagchi gave oral evidence. He remained of the view that Sudiksha did not lack capacity to make decisions about her medical treatment. Dr Bagchi explained that she was in denial about the imminence of her death as expressed by the doctors. Her view was informed by both her religious faith and the love and support of her family. Dr Bagchi described this not as a "false belief" but as a "different opinion". Sudiksha did not want palliative care and she was not delusional in expressing that view. In conclusion, when asked specifically by Mr Horne KC who represented the Official Solicitor below, he said he could find no impairment in the functioning of the mind.

Dr Mynors-Wallis:

73. Dr Laurence Mynors-Wallis is a Consultant Psychiatrist at the Dorset Healthcare University NHS Trust and Visiting Professor at Bournemouth University. Dr Mynors-Wallis was instructed by the Trust to undertake an independent assessment of Sudiksha's capacity. In his first report dated 23 April 2023, he concluded that Sudiksha lacked capacity to make decisions about her care and treatmentin relation to medical treatment. In the second, dated 5 August 2023, he expressed the opinion that "on the balance of probabilities [Sudiksha] has capacity to make decisions about her care and treatment."

74. Dr Mynors-Wallis first saw Sudiksha and her mother on 21 April 2023. Sudiksha refused to speak to him. It was against the backdrop of Sudiksha refusing to engage with him that Dr Mynors-Wallis formed the opinion expressed in his first report, namely that Sudiksha lacked capacity to make decisions about her care and treatment.

75. Unlike Dr Bagchi, Dr Mynors-Wallis conducted his analysis by reference to the Mental Capacity Act, first considering the four functional tests of capacity before moving on to consider the diagnostic test.

76. In Dr Mynors-Wallis' opinion, Sudiksha did not understand the nature of her illness as she did not accept that she was in the final stages of her illness. She did not trust the doctors and did not believe what they said, which meant that she was unable to weigh up information provided to her by medical staff. She therefore 'failed' the functional test and was 'unable to make a decision' for the purposes of section 2(1) MCA.

77. The question remained as to whether this inability to make a decision was because of an impairment of mind. Dr Mynors-Wallis explained his conclusion by reference to a large-scale study which had been conducted called the "Intensive Care Outcomes Network Study". The study concluded that even after a matter of days, people who had been in ICU developed symptoms of anxiety, depression and of Post Traumatic Stress Disorder. Given the length of time Sudiksha had been in ICU, and that she was unlikely ever to be discharged, Dr Mynors-Wallis said that it was highly likely that even though she was not expressing any symptoms of anxiety or depression, they were very likely to be present.

78. Further, he thought that at only 19 years old, Sudiksha was unlikely to have been able to build up the emotional resilience necessary to enable her to cope with the significant stresses she faced.

79. Dr Mynors-Wallis concluded that Sudiksha was not therefore able to make any decisions of any consequence about her care and treatment. She had, he said in his first report, an impairment of mind because of the following features:

> "i) the particularly distressing and pervasive nature of her physical health problems and the impact this must have had on her mind.
>
> ii) The impact of a prolonged stay on ICU.
>
> iii) Sudiksha's refusal and great distress when being asked by me to participate in an ongoing evaluation of her wishes and feelings.
>
> iv) Sudiksha's agitation when being asked by Dr Bagchi about her physical condition.
>
> v) Sudiksha's fixed beliefs about not trusting ward doctors and her fixed decision and refusal to discuss anything with me indicates, in my opinion, an inability for flexible decision making and to hold in her mind competing ideas."

80. Following the serious deterioration in Sudiksha's condition in July 2023, Peel J made directions for the issue of capacity to be litigated. It was in this context that the parents submitted that further evidence from Dr Mynors-Wallis was required.

81. In preparation for this second report, Dr Mynors-Wallis was able to speak to Sudiksha, her parents and her brother for approaching two hours.

82. Dr Mynors-Wallis discussed with Sudiksha the potential success of nucleoside therapy. Sudiksha thought that the potential benefit was 50% but poignantly and, in my view, significantly said: "*[t]his is my wish. I want to die trying to live. We have to try everything*". The whole family thought that any chance was better than no chance at all.

83. Dr Mynors-Wallis was satisfied that Sudiksha could follow the discussion. She was "animated and engaged and interjected spontaneously when she wished to express a view about her treatment or wishes". She was clear that she would put up with pain and discomfort if it meant she could have nucleoside therapy which she thought had a 50%

chance of success. Dr Mynors-Wallis saw no evidence of anxiety or agitation. At the end of the session, he recorded in his report that she had thanked him for coming and had apologised for not speaking to him at the previous appointment.

84. Dr Mynors-Wallis having assessed Sudiksha, remained of the view that she did not meet all four limbs of the functional test. He then turned to consider whether her failure to meet the section 3 functional test of capacity was *because of* an impairment of mind.

85. Having had the opportunity of interviewing Sudiksha, Dr Mynors-Wallis said that he had underestimated Sudiksha's resilience and how the positive stance of her family had contributed to her continuing hope for improvement and her ability to plan for the future, without her being overwhelmed by her significant physical health problems. Any episodes of distress recorded in the notes he observed, were not reported as pervasive or continuing.

86. In oral evidence, Dr Mynors-Wallis' stated his opinion, that Sudiksha's belief that she could live was "completely understandable in the social context in which Sudiksha found herself". "She was not delusional, it was rational and logical in the context of Sudiksha and the three people with whom she is spending her entire time, each believing that the doctors have not always got it right, that there is treatment that has a chance of working and that that is something that is actually worth holding out for". Dr Mynors-Wallis said that the "wrong belief", which meant that she failed the functional test, was not because of an impairment of mind, but because that was what Sudiksha was told by her family "whom she trusts and loves".

87. In his oral evidence, Dr Mynors-Wallis reiterated that whilst Sudiksha failed the functional test, an impairment of mind has to be something separate. A false belief, he said, in itself is not evidence of impairment. He explained that there has to be something else because the impairment has to be "because of". "You do not need a psychiatric syndrome or diagnosis … you need something … there must be something to lead to that impairment, not simply a belief in itself". Dr Mynors-Wallis therefore regarded 'belief' as a necessary requirement at the functional stage but not at the mental impairment stage.

88. Dr Mynors-Wallis, now having met Sudiksha, confirmed the view of all who came into contact with her in the year in which she was a patient in ICU, namely that she was a "remarkable young woman in many ways and had a remarkable resilience to what she was facing and it was her remarkable family that had given her that resilience". He pointed out that Dr Bagchi had seen her numerous times and not made a diagnosis of PTSD.

89. Dr Mynors-Wallis told the court that he had "put diagnosis on the back burner" and was looking for impairment but that he "could not convince myself that there was an impairment.". He said that he had looked for evidence of impairment, but although she was making decisions based on false beliefs the decision that she did not want to stop active treatment was a capacitous decision. "A capacitous decision because she wanted to stay alive despite the discomfort, and she does not want to be given up on".

90. Dr Mynors-Wallis concluded in his written report that Sudiksha's "failure to understand the nature of her illness and hence be able to weigh up the facts in a decision making

process is not because of an impairment of mind but rather a result of the shared beliefs that she holds with her family".

91. Dr Tunnicliffe gave oral evidence on behalf of the Trust whose position at the beginning of the hearing was that Sudiksha was delusional and as a consequence was suffering from an impairment of mind. Dr Tunnicliffe told the court that he had seen Sudiksha on 31 July 2023, a few days before the hearing. He described her in his written evidence as having been "alert and engaged throughout and was as bright as I have seen her over the past months". There was, he said, no problem with communicating with her and no evidence of brain damage as a result of the respiratory arrests she had recently experienced. Dr Tunnicliffe believed that she was capable of retaining and weighing up information not only about her day-to-day care needs, but also many of the more complex aspects of the care she was receiving. The difficulty, he said, was that Sudiksha had what he described as a "deeply seated misunderstanding" of her illness because she could not contemplate an outcome inconsistent with her conviction that she could and would recover. She could not, Dr Tunnicliffe said, address her mind to weighing up alternative options, including palliative care and what that might involve.

92. Dr Tunnicliffe said in his evidence in chief that his concern was that she was unable to weigh up the pros and cons of a "dignified death". She was, he said, suffering from a delusion which derived from a false reality in that she could not contemplate her own death. When cross-examined, Dr Tunnicliffe accepted that the prognosis given to the family as to the timescales before her death had been wrong in the past and that it was difficult to say what would happen next. In his opinion, her survival was likely to be measured in days, weeks or maybe a month. The likely benefits of nucleoside treatment were "vanishingly small". Dr Tunnicliffe accepted, however, that a hope on the part of Sudiksha to survive in a stable condition until receipt of an offer to go to the United Sates or Canada, in circumstances where she also recognised that alternative palliative care may become necessary in the event of a critical deterioration, could not be said to amount to a delusion. The problem was, he said, that he could see no acceptance on Sudiksha's part that the most likely route for her would be that she would destabilise and die.

93. Having read the transcripts with care, it is apparent to me that when the label of delusional was tested in cross examination, Dr Tunnicliffe moved away from MCA mental impairment test, and it became clear that, for wholly understandable reasons, when Dr Tunnicliffe said that whilst he had no wish to remove hope: "[w]e need to write the menu for her to choose" and that, "[w]e need to offer treatments that are appropriate and available", he was speaking far more in terms of best interests than the MCA.

94. The Official Solicitor submitted that Sudiksha's belief system was entirely consistent with the range of capacitous decisions that any 19-year-old may make who wants to live and who believes that every reasonable active effort should be made to give her every chance of surviving.

The Judgment

95. The judge explained at [2] that the collective clinical view was that Sudiksha was reaching the final stage of her life. Having heard Dr Tunnicliffe give oral evidence at [3] the judge said that that did not mean that death was necessarily imminent as

Sudiksha may have had weeks, or even months, to live. The Trust, she said, had been met with a "fundamental obstacle" in trying to preserve her autonomy to make choices as to what steps might be taken to make her last days or weeks comfortable and pain free. The obstacle was "her apparent refusal or inability to accept that her disease will result in her early if not imminent death. It is that inability, or "delusion", which the Trust relied on as rendering her incapacitous to make decisions for herself".

96. The judge summarised Sudiksha's position as follows:

> "6. [Sudiksha] is well aware that she has been offered a very poor prognosis by her doctors. She acknowledges that they have told her that she will die but she does not believe them. She points to her recovery from previous life-threatening episodes whilst she has been a patient at the intensive care unit. She believes she has the resilience and strength to stay alive for long enough to undergo treatment abroad and she wishes the court to acknowledge her right to make that decision for herself."

97. Having set out the relevant sections of the MCA, the judge identified the two questions she needed to answer in order to decide Sudiksha's capacity in relation to her medical treatment:

> "17. The court must therefore address two specific questions in order to determine the issue of capacity in this case. First, is [Sudiksha] unable to make decisions for herself in relation to ….(b) her current and future medical treatment including the level of medical intervention going forward; the stage at which that medical intervention should be reduced or withdrawn; and whether to embark on a trial of nucleoside therapy, if it becomes available to her in circumstances where there are no available or reliable predictors of outcome? Second, if she is unable to make decisions in either domain, does that inability arise because of an impairment of, or a disturbance in the functioning of, her mind or brain?
>
> "18. In the context of the first question as it applies in the context of current and future medical treatment, and before turning to consider the detail of the medical evidence before the court, I consider that the broad parameters of the relevant information includes an understanding or appreciation of (i) the nature of her disease; (ii) the assessment of her treating clinicians in relation to prognosis; (iii) the options available in terms of active treatment going forward including the likelihood of such treatment being available to her and its chances of success; (iv) the reasonably foreseeable consequences for her of withdrawing active treatment and moving towards a path of palliative care; and (v) the reasonably foreseeable consequences of continuing with current medical interventions in the context of the possibility of further pain, anxiety and distress generally and in the event of further unexpected medical events."

98. The judge dealt at some length with the evidence of Dr Tunnicliffe before moving on to summarise the reports and oral evidence of Dr Bagchi and Dr Mynors-Wallis. At [42] she recorded that Dr Bagchi's expert view was that Sudiksha was in denial about the imminence of her death but that she had a strong view that "she would come through one day". That view was informed by her religious faith and the love and support of her family. She was clear she did not want palliative care. These were not, Dr Bagchi said, fixed or delusional views but shaped by information about possible overseas trials, but above all by a wish to stay alive as long as possible.

99. The judge's analysis of Dr Mynors-Wallis' evidence starts at [44] of her judgment. His first report is dealt with at [44]. Unfortunately, the judge fell into error at this early stage of her analysis of Dr Mynors-Wallis' evidence as she said "[h]is first report in April 2023 had reached no specific conclusions because [Sudiksha] was unwilling to engage with him at that time". In fact, as set out at [79] above, Dr Mynors-Wallis had unequivocally expressed the view in his first report that Sudiksha lacked capacity to consent to medical treatment and had set out those matters which had informed his decision.

100. The judge moved on to the second report of July 2023 noting that Sudiksha had this time been willing to engage with Dr Mynors-Wallis about what might be involved in a decision to move to palliative care and that, having spoken to her, his conclusion was now in common with Dr Bagchi, that Sudiksha had capacity in relation to medical treatment.

101. Dr Mynors-Wallis had been asked in cross-examination about his opinion that Sudiksha's beliefs were anchored in beliefs she shares with her family. The judge summarised his response at [55-56]:

> "He said that he did not regard the basis of those beliefs as completely irrational. The fact that enquiries had been made of three potential providers of experimental treatment who had asked for further information was evidence that there was a rational basis for a belief that treatment might be available, albeit that such treatment was untried and untested. Dr [Mynors-Wallis] had formed a view that in circumstances where the three most important people in [Sudiksha's] life were clinging to the same hope, it was understandable that she should also focus on this "light in the tunnel" even if that light was extremely dim. Further in circumstances where Dr [Tunnicliffe] had expressed the prognosis for [Sudiksha] in an earlier statement as one where she had only "hours or days" to live, and where [Sudiksha] had confounded those expectations, he did not consider that her beliefs could be seen as delusional.
>
> 56. In response to questions put to him by Mr Sachdeva KC on behalf of the Trust, Dr [Mynors-Wallis] said that, whilst wrong in her false belief that nucleoside therapy will bring any improvement in her current condition, it is an understandable belief which derives significant support from the beliefs held by her family members. He viewed her decision that she did not want to abandon active treatment as a capacitous

> decision. When cross-examined by Mr Garrido KC, he confirmed that the entire body of medical opinion available to the court supports his belief that she does not have a realistic appreciation of the likely outcome of treatment and he concurs with that opinion. That is the basis of his view that she fails the functional test for capacity".

102. The judge at [57] explained that she herself had gone on to explore this aspect of Dr Mynors-Wallis' evidence with him. He had told the judge that:

> "Her beliefs are such that she does not understand her illness sufficiently to make a capacitous decision as to whether to go down a palliative path [of care], but that is not the result of any impairment of mind or disturbance of the brain. Rather it is a belief which she shares with her family. So within the meaning of the Act, I believe she has capacity. …. What she does not have is an understanding of the inevitability of a decline and that her hopes will not be fulfilled."

103. The judge having accurately recorded Dr Mynors-Wallis' final opinion as contained in his second report and confirmed in his oral evidence, started, at [77], her analysis in accordance with *JB*, by reference to the functional test. She said that at the heart of the dispute was Sudiksha's ability to use and weigh up the information she had been given in relation to "both the treatment options which she and her family wish to explore and the alternative of palliative care should the prognosis offered by her treating clinicians be correct, even if the precise timescales are unpredictable" [76].

104. The judge identified the "fundamental aspects of the relevant information" including the nature of the disease, the prognosis, the available options of active treatment and the likelihood of success.

105. The judge said in relation to the functional test that:

> "78. In terms of the functional test of capacity, a person's ability to understand, use and weigh information as part of *the process of making a decision depends on him or her believing that the information provided for these purposes is reliable and true.* That proposition is grounded in objective logic and supported by case law in the context of both the common law and the interpretation of MCA 2005." (*my emphasis)*

106. The judge quoted Butler-Sloss LJ in *Re MB* and Munby J in *Re MM* and the application of Munby J's 'subsumed' approach to belief in *Re MPZ*. The judge went on to apply the 'belief' test to Sudiksha's circumstances:

> "84. …What she fails to understand, or acknowledge, is the precariousness of her current prognosis. She does not *believe* that her doctors are giving her true or reliable information when they tell her that she may have only days or weeks to live. She refuses to contemplate that this information may be true or a reliable prognosis because she has confounded

> their expectations in the past despite two acute life-threatening episodes in July this year and because she has an overwhelming desire to survive, whatever that may take".

107. The judge having accepted that it is the mitochondrial disease causing the progressive failure of her respiratory muscles and not Long Covid as Sudiksha believed, said that:

> "86. Because she clings to hope that her doctors are wrong, she has approached decisions in relation to her future medical treatment on the basis that any available form of treatment is a better option than palliative care which is likely to result in an early death as active treatment is withdrawn. In my judgment she has not been able to weigh these alternatives on an informed basis because (a) she does not believe what her doctors are telling her about the trajectory of her disease and her likely life expectancy, and (b) she does not fully comprehend or understand what may be involved in pursuing the alternative option of experimental nucleoside treatment. Whilst I accept that she recognises that it may not be successful in terms of the outcome which she wishes to achieve, she has failed to factor into her decision-making that there are, as yet, no concrete funded offers of treatment, far less offers which might offer her even the smallest prospect of a successful outcome."

108. In concluding her analysis of the functional test, the judge agreed with Dr Mynors-Wallis that Sudiksha failed the functional test saying:

> "93. In my judgment the answer to the first question posed in *JB* (above) is that [Sudiksha] is unable to make a decision for herself in relation to her future medical treatment, including the proposed move to palliative care, because she does not believe the information she has been given by her doctors. Absent that belief, she cannot use or weigh that information as part of the process of making the decision. This is a very different position from the act of making an unwise, but otherwise capacitous, decision. An unwise decision involves the juxtaposition of both an objective overview of the wisdom of a decision to act one way or another and the subjective reasons informing that person's decision to elect to take a particular course. However unwise, the decision must nevertheless involve that essential understanding of the information and the use, weighing and balancing of the information in order to reach a decision. In [Sudiksha's] case, an essential element of the process of decision-making is missing because she is unable to use or weigh information which has been shown to be both reliable and true."

109. Having concluded that Sudiksha had failed the functional test because she lacked the necessary belief in the information given to her by the treating clinicians, the judge moved on to the mental impairment test and considered whether Sudiksha's inability to make a decision for herself was because of an impairment of the mind. The judge said that Sudiksha was able to recognise that without experimental treatment she will die:

> "95.…In my judgment she refuses to contemplate when her death may occur because she has invested all her remaining physical, emotional and spiritual energy in staying alive and pursuing the option of alternative treatments. She cannot contemplate that her doctors may be right in their assessment of her prognosis because she does not recognise or believe that her progressive respiratory failure is a symptomatic manifestation of the course of the disease and she has managed to survive to this point in time despite their attempts to persuade her that she is dying."

110. The judge reminded herself by reference to *North Bristol,* that the question is whether the person is rendered unable to make the decision by reason of the impairment, which she said was a question of fact for the court:

> "98. As to the nature of the impairment of, or disturbance in the functioning of, the mind or brain which prevents [Sudiksha] from understanding, using and weighing the information which she has been given, it is accepted that [Sudiksha] does not suffer from any recognised psychiatric or psychological illness. Dr Mynors-Wallis struggled to identify precisely how to 'label' [Sudiksha's] condition. His evidence was that her beliefs, which he accepted to be false, did not amount to a delusion because there was an understandable basis for her views which derived from, or coincided with, the views held by those she loved and trusted. *His concern about making the causal nexus between a lack of ability to make a decision and the impairment in question was that none of the treating clinicians had identified a physical problem in her brain or that her recent respiratory arrests had affected her the functioning of her brain.* That much is agreed." *(my emphasis*)

111. With respect to the judge, that is not, in my judgment, a correct analysis of why Dr Mynors-Wallis concluded that Sudiksha's inability to use and weigh up the relevant information was not *because of* an impairment of the mind. It was not the case that he had concluded that she had capacity because he, as a psychiatrist, had been unable to make the necessary casual connection absent a "physical problem in her brain". He recognised that Sudiksha was not suffering from a mental illness and that she was not delusional. On the contrary, he had found her to be an "animated individual, able to engage and participate in the discussion". That, however, was not why he concluded that her inability to use and weigh the information was not because of an impairment of mind. Rather he had reached that conclusion as a consequence of his expert assessment at interview.

112. Having spoken to Sudiksha and the family, Dr Mynors-Wallis had concluded that in his first report he had underestimated her resilience and how the positive stance of her family had contributed to her continued hope for the future together with her ability to "plan for the future without being overwhelmed by her significant physical health problems". Further, he believed it was significant that, although the medical records showed occasions when she had been distressed or anxious, these were not reported as pervasive or continuing. Sudiksha had had no ongoing mental health problems and had

not required medication or specialist psychological treatment during the year she had been on ICU. These were the features that, notwithstanding her inability to accept her desperate prognosis, had led him to conclude that there was no impairment of the mind and not because of his inability to identify 'a physical problem in her brain or that her recent respiratory arrests had affected the functioning of her brain'.

113. It follows that once Dr Mynors-Wallis had seen and assessed Sudiksha, he had concluded that she did not fit the expected presentation of a patient in her position as described in the research and upon which he had relied for his conclusion that she lacked capacity when he had prepared his first report.

114. Whilst the judge did not find it helpful to frame the enquiry in terms of whether Sudiksha was delusional as had been done by the Trust, the judge made no further reference to Dr Mynors-Wallis' analysis contained in his second report as to why Sudiksha's unrealistic beliefs about the potential benefits of nucleoside therapy were not the result of an impairment of mind, but rather the result of the close relationship that she had with her family and their shared belief that there was a prospect of recovery.

115. The judge for the purposes of reaching her conclusion as to capacity reverted instead to the content of Dr Mynors-Wallis' first report written at a time when he had not seen Sudiksha and which had necessarily been based on a number of assumptions which, absent clinical assessment, he would have expected to apply to a 19-year-old who had spent twelve months in ICU. The judge said:

> "103. In my judgment, and based upon the evidence which is now before the court, I find on the balance of probabilities that [Sudiksha's] complete inability to accept the medical reality of her position, or to contemplate the possibility that her doctors may be giving her accurate information, is likely to be the result of an impairment of, or a disturbance in the functioning of, her mind or brain. Her vulnerability has been acknowledged by [Dr Mynors-Wallis]. I need no persuading that she has been adversely impacted by the trauma of her initial admission to hospital. That trauma is likely to have been exacerbated by the length of her stay in the ITU unit. Her brother acknowledges that she has been surrounded by patients dying around her on the unit as the months have gone by. Whilst she has been sustained by the near continuous presence of her mother and, to a lesser extent, the other members of her close family, she has endured almost a year of intensive medical and surgical intervention which has been both painful and distressing for her. She is frightened by the prospect of dying and clings to her desire to survive what her doctors have repeatedly told her is an unsurvivable condition. The cumulative effect of her circumstances over such a prolonged period, her profound inability to contemplate the reality of her prognosis, and a fundamentally illogical or irrational refusal to contemplate an alternative are all likely to have contributed to impaired functioning notwithstanding the resilience which [Sudiksha] has displayed in her determination to carry on fighting. It is not necessary for me to seek to further define the nature of that

> impairment. I am satisfied that it exists and that it operates so as to render her unable to make a decision for herself in relation to her future medical treatment.
>
> 104.… It is not simply the failure to believe the advice she is receiving and thus her inability to understand, use and weigh information in the decision-making process which informs the finding of impairment. It is informed by a holistic evidence-based overview of [Sudiksha's] lived experience on the ITU and the trauma she has suffered as a result of the intensive treatment she has required over the past twelve months. That trauma has manifested itself in acute episodes of distress and anxiety and a presentation which suggests a hyper-vigilant state where she is continuously watching for her mother and requiring her constant support on an almost daily basis."

116. It can be seen therefore that the judge's view that Sudiksha lacked capacity rested on her finding that belief was an essential ingredient before a person can be said to understand and to weigh up and use information for the purposes of the functional test. In turn, that lack of belief together with the theoretical impact of her long term stay in ICU as described in Dr Mynors-Wallis' first report, informed her finding of impairment as set out at [110] above.

117. The judge did not specifically acknowledge in her judgment that both the experts and the Official Solicitor acting on her behalf said that Sudiksha had capacity to make decisions about her medical treatment. Even the Trust was, in my analysis, driven to attempt to shoehorn into the term "delusional" what in reality they regarded as a profoundly unwise decision on Sudiksha's part to refuse to move to palliative care, a decision they felt to be contrary to her best interests. Whilst it was the case that Dr Bagchi did not apply the MCA two stage test, he was the 'in house' psychiatrist who had seen her numerous times over the year that she had been in ICU and on four occasions recently. As Dr Mynors-Wallis rightly observed, Dr Bagchi was a very experienced psychiatrist who had seen Sudiksha regularly and his opinion that Sudiksha had capacity, deserved respect. In my judgment, the first stage in the analysis, where a judge disagrees with unanimous expert opinion, is to identify the common view and to recognise that that is the position before moving on to give reasons for not accepting that unanimous view.

118. In the event, the judge gave no reasons for rejecting the combined expert opinion or more specifically for having rejected the second report of Dr Mynors-Wallis, nor did she analyse the reasons for his change of opinion between the two reports, but rather based her decision, contrary to the weight of the expert evidence, on the first report which had been prepared without the benefit of his having interviewed Sudiksha.

119. I cannot accept Mr Sachdeva's characterisation of Dr Mynors-Wallis' change of opinion between his first and second report as a *volte face* which justified the judge in ignoring the second report and relying exclusively on the first report. The second report was not a sudden and complete change in opinion, but rather it was a carefully considered and justified change of view made after having seen Sudiksha and her family in person over an extended period of time.

120. In my judgment, the judge fell into error in relying on his first report and did not give sufficient reasons for disagreeing with the unanimous view of both experts, the Official Solicitor and the modified view of Dr Tunnicliffe.

The Grounds of Appeal

121. The Grounds of Appeal are that the judge erred "in the following ways":

> "Ground 1: By departing from the clear and unequivocal conclusions of the two court-appointed psychiatric experts whilst failing, contrary to the requirement laid out by the Court of Appeal in *AB v BG & Ors* [2009] EWCA Civ 10, to: (i) base this departure on material upon which a disagreement could be founded; (ii) give adequate reasons for this departure."
>
> Ground 2: By treating the opinion of the non-expert clinical witnesses as being to all intents and purposes equivalent to that of the experts.
>
> Ground 3: By holding, contrary to the Court of Appeal in *Re D (Children)* [2015] EWCA Civ 749, that the diagnostic test in MCA 2005 did not require as a matter of necessity the professional diagnosis of an impairment of the mind.
>
> Ground 4: By premising its assessment of capacity on substantively accepting disputed, untested opinion evidence about [Sudiksha's] physical condition, prognosis and treatment options which had been expressly excluded from the scope of the hearing.
>
> Ground 5: By adopting an approach which placed the functional test of capacity before the diagnostic test contrary to the requirements of the MCA Code of Practice and thereby failing to comply with s. 42(5) MCA.
>
> Ground 6: By finding that a lack of belief in a diagnosis or prognosis may amount to a lack of understanding for the purposes of s.3(1) MCA health and welfare decision-making in circumstances where there was a rational basis for the lack of belief."

122. The best place to start in the analysis is Ground 6 "belief" which in turn feeds into Grounds 1 and 2, the role of the experts and the reasons for which the judge disagreed with their opinions.

123. As discussed above in my judgment from paragraphs [48] to [60] above, there is no specific requirement of belief, whether subsumed into the general requirement of understanding or in the ability to use and weigh information or otherwise. In as much as this Court is influenced by any of the pre-MCA cases, in my view the proper approach is that of Butler-Sloss LJ in *Re MB*: an absence of belief *may* but not inevitably will, on the facts of a particular case, lead to a clinician or a court to conclude

that the functional test in section 3(1) is not satisfied and that the person in question does not have the ability to make the decision in question.

124. All that is required is an application of the statutory words without any gloss. "Does this person have the ability to understand?", "Is this person able to use and weigh this information?" The danger is that the introduction of the word "belief" is either the same as the statutory test, in which case it is otiose or, if that is not the case, there is the risk that by introducing a hard-edged requirement of 'belief' people will look for something different from the statutory test which is wrong in law. All that is required is the application of the words of the statute.

125. Unsurprisingly, both the judge and Dr Mynors-Wallis approached the case on the basis that Sudiksha's inability to believe that she was going to die soon and that nucleoside experimental treatment was not going to help, led inexorably to the conclusion that she was unable to satisfy the functional test as she did not understand the information and was unable to weigh and use it.

126. The judge at [93] agreed with Dr Mynors-Wallis that Sudiksha was "unable to make a decision for herself in relation to her future medical care, because she does not believe the information she has been given by her doctors, absent that belief, she cannot use or weigh that information as part of the process of making the decision".

127. She then moved on to consider (essentially by reference to Dr Mynors-Wallis' first report) whether Sudiksha was unable to make a decision in relation to her medical treatment because of an impairment of mind. The judge's approach at [103] (paragraph [114] above) to belief/acceptance again fed into this critical issue: "her complete inability to accept the medical reality … is likely to be the result of an impairment of mind".

128. Whilst the wording of Ground 6 is somewhat confusing, the appeal has been argued by all parties on the basis that the alleged error of law on the part of the judge was in relation to her approach to the statutory test in saying that Sudiksha's refusal or inability to believe the 'information' alone resulted in her failing the functional test in section 3(1) MCA. It follows in my judgment that the appeal must succeed on this ground as, for the reasons set out above, the judge made an error of law in regarding the absence of belief as determinative of the functional test. This was an error made through no fault of her own given that she was applying the test as set out by Munby J in *Re MM*.

129. It follows that the Trust's concession was well made. The proper application of the statutory test does no more than reflect that, where there is an objectively verifiable medical consensus as to the consequences of having or not having medical treatment, if the patient does not believe or accept that information to be true, it may be that they are unable to understand and or use and weigh the information in question.

130. In the event, it is not necessary for the court to determine whether, upon the application of the less absolute test in relation to belief, the court would have still concluded that Sudiksha was unable to make a decision for the purposes of the functional test. That is because, this Court has decided, for the reasons given below in relation to Grounds 1 and 2, that the judge fell into further error in rejecting the unanimous expert evidence as to capacity.

131. Grounds 1 and 2 relate to the fact that the judge, having dismissed the Trust's submission that the mental impairment test was satisfied by virtue of Sudiksha's views being 'delusional', thereafter failed to give adequate reasons for departing from the conclusion reached by each of the two experts that Sudiksha had capacity, which expert view was endorsed by the Official Solicitor's own observations of Sudiksha.

132. That judges are entitled to disagree with an expert witness needs no rehearsing. In *AB v BG (Re G and B (Fact -Finding hearing)* [2009] EWCA Civ 10, Wall LJ *("AB v BG")* said at [17] that that proposition has an "equally obvious corollary". There must, he said, be "material upon which the judge in question can safely found his or her disagreement, and he or she must fully explain the reasons for rejecting the expert's evidence."

133. Turning once again to *King's College*, MacDonald J said:

> "39. Finally, whilst the evidence of psychiatrists is likely to be determinative of the issue of whether there is an impairment of the mind for the purposes of s 2(1) , the decision as to capacity is a judgment for the court to make (see *Re SB [2013] EWHC 1417 (COP)*). In *PH v A Local Authority* [2011] EWHC 1704 (COP) Baker J observed as follows at [16]:
>
> > 'In assessing the question of capacity, the court must consider all the relevant evidence. Clearly, the opinion of an independently-instructed expert will be likely to be of very considerable importance, but in many cases the evidence of other clinicians and professionals who have experience of treating and working with P will be just as important and in some cases more important. In assessing that evidence, the court must be aware of the difficulties which may arise as a result of the close professional relationship between the clinicians treating, and the key professionals working with, P.'"

134. Mr Quintavalle in oral argument, sought to go significantly further than either *AB v BG* or *King's College.* He submitted that a judge cannot disagree with the opinion of an expert absent there being available to the court other alternative expert medical evidence in support of the judge's view. In other words, Mr Quintavalle appeared to submit that a judge may not disagree with a unanimous view of experts, but may only decide as between more than one opposing expert view. That cannot be right, although it is undoubtedly the case that where the judge disagrees with a unanimous view which has been expressed by appropriate experts, a reader will look carefully to understand the judge's "full explanation" for having rejected that common view and for the identification by the judge of the material upon which their disagreement is based.

135. In the present case, the judge was faced with the united view of Dr Bagchi and Dr Mynors-Wallis, the endorsement of the Official Solicitor (who had the advantage of having ascertained Sudiksha's wishes) and of Dr Tunnicliffe's virtual concession that his 'delusion' position was not sustainable and that what he was in reality concerned about was the right best interests decision for Sudiksha.

136. Critically also, the judge's reasons for rejecting the views of the experts who (notwithstanding their error in relation to belief) were of the view that Sudiksha had capacity, had to be considered and explained against the statutory presumption of capacity, the principle of autonomy and the fact that an unwise decision is not an incapacitous decision.

137. In my judgment, the judge fell into error in her approach which was essentially to adopt Dr Mynors-Wallis' first report with no analysis as to why it was to be preferred to his second report which had been written having seen and assessed Sudiksha and which dovetailed with Dr Bagchi who had had the advantage of seeing her on a number of occasions including in the absence of her family.

138. Once one displaces an absolute requirement for "belief", then, where a 19-year-old young woman, fully conscious and suffering no identifiable mental illness or loss of brain function and with the full support of her close knit family, refuses to accept that her death is imminent but says loud and clear to two psychiatrists that she wants to "*[d]ie trying to live*", it will take a great deal to displace the principle of autonomy and the presumption of capacity, no matter how unwise her decision to eschew palliative care may have seemed to a more mature mind.

139. It follows that against that backdrop, the judge in my judgment, failed to give sufficient reasons for disagreeing with the unanimous view of the experts that Sudiksha had capacity to make decisions as to her medical treatment.

140. The other Grounds of Appeal, each of which I would dismiss, need only be dealt with in the briefest of terms:

    i) Ground 3: professional diagnosis of an impairment of the mind:

    Re D (Children) [2015] EWCA Civ 749 did not, as implied in this ground, say that a professional diagnosis of an impairment of mind is required before it can be said to have been established. In *Re D* at [30], I simply said that the diagnostic test will require evidence from a suitably qualified person, which will usually be a person with medical qualifications. This was said in the context of a case where it was agreed that the person in question suffered from significant learning difficulties. In case there is any room for misunderstanding, I make it absolutely clear that I endorse the approach of MacDonald J in *North Bristol* that no formal diagnosis of impairment is required.

    ii) Ground 4: evidence of Sudiksha's condition, prognosis and treatment options:

    The judge heard and accepted the evidence of Dr Tunnicliffe who was the principal clinical lead whose evidence was tested in cross-examination. The judge had the advantage of extensive medical evidence from a number of differing disciplines, often accompanied by independent second opinions. That Sudiksha was in the terminal stage of her illness was undoubtedly the case. What was not being considered at the hearing was what further treatment would or would not be in her best interests. That was an issue which, had she lived long enough for a court to have considered it, would no doubt have been the subject of challenge by the clinicians.

iii) Ground 5: Application of *Re JB* to the present case:

Mr Quintavalle submitted that the test in *JB* did not apply because in *JB*, unlike the present case, there was no doubt that the patient concerned had an impairment of mind and the issue there was as to whether, notwithstanding that impairment, the patient could consent to treatment. Mr Quintavalle drew the attention of the Court to the Mental Capacity Act 2005 Code of Practice ("the Code") which stipulates the two-stage test of capacity, the first stage (at 4.11) being to establish whether someone has an impairment i.e. the diagnostic test. In this context he draws the attention of the court to section 42(5) MCA which requires the Court to "take into account" the Code.

Responding to this submission, Mr Sachdeva rightly drew the Court's attention to *Lawson, Mottram and Hopton, Re(Appointment of personal welfare deputies)* [2019] EWCOP 22; [2019] 1 WLR 5164 at [16] which makes it clear that it is the wording of the statute as authoritatively interpreted by the Court which must prevail over the Code. In my judgment, this and indeed any court, is in any event, bound by the Supreme Court decision in *JB* namely that questions under section 2(1) MCA should be first as to whether P is unable to make a decision for themselves by reference to section 3(1), the functional test. If they are not so able, consideration is given at the second stage to whether that inability is because of an impairment of, or a disturbance in, the functioning of the mind or brain (section 2(1), the mental impairment test).

I should say for completeness sake, that the Code with which the Court is concerned was first published in 2007. A consultation ran between March and July 2022 in relation to the proposed updating and revision of the Code. The Consultation said that the Code was to be revised because: "the existing Code guidance needs updating in light of new legislation and case law, organisational and terminological changes, and developments in ways of working and good practice". The draft new Code, dated June 2022, adopts the *JB* approach to assessment of capacity at chapter 4.

Conclusion and Outcome

141. The appeal is therefore allowed on Grounds 1, 2 and 6 and dismissed on Grounds 3, 4 and 5.

142. The declaration of incapacity having been set aside the presumption of capacity applied. It follows that in my judgment, this remarkable young woman had capacity to make decisions in relation to her medical treatment and therefore had her wish to "*die trying to live*".

Lord Justice Singh:

143. I agree.

Lord Justice Baker:

144. I also agree.