



Neutral Citation Number: [2023] EWCOP 40

Case No: 1405715T

IN THE COURT OF PROTECTION
In the matter of the Mental Capacity Act 2005
And in the matter of ST

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25/08/2023

Before :

THE HONOURABLE MRS JUSTICE ROBERTS

Between :

A NHS TRUST (“The Trust”)	<u>Applicant</u>
- and -	
(1) ST (by her litigation friend, the Official Solicitor)	<u>Respondents</u>
(2) TH	
(3) RT	

Vikram Sachdeva KC (instructed by Bevan Brittan) for the Applicant
Michael Horne KC (instructed by the Official Solicitor) for the First Respondent
The second and third respondents appeared in person with ST’s brother, VC
Damian Garrido KC and **Bruno Quintavalle** appeared at the invitation of the court having
been instructed by Moore Barlow LLP on behalf of ST

Hearing date: 7 August 2023

Approved Judgment

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

.....
THE HONOURABLE MRS JUSTICE ROBERTS
The judge has given leave for this version of the judgment to be published.

Mrs Justice Roberts:

1. ST is 19 years old. Despite a school career in mainstream education where she was studying for her A levels, she has spent the past year as a patient in an intensive care unit run by the Hospital Trust which brings this application. She has a rare mitochondrial disorder which is a progressively degenerative disease. According to the expert¹ evidence which is before the court, there is no cure which might enable ST to resume her life outside the clinical setting of the intensive care unit. She is mechanically ventilated through a tracheostomy. She is fed through a percutaneous endoscopic gastrostomy tube and is currently undergoing regular haemodialysis. Her disease has resulted in a number of related health problems including impaired sight and hearing loss, chronic muscle weakness, bone disease and chronic damage to her kidneys and lungs.
2. The collective view of her treating hospital clinicians is that ST is now in, or fast approaching, the final stage of her life. In February this year, as her condition appeared to worsen, the Trust issued these proceedings to determine the validity of a lasting power of attorney which ST had apparently signed some three months earlier and, specifically, to seek declarations in relation to her capacity and her future medical treatment. The matter comes before me as a result of directions given by Mr Justice Peel on 26 July 2023. The issues for determination at this hearing are ST's capacity (i) to litigate and (ii) to make her own decisions in relation to future medical treatment. The Trust's intention is to move to a treatment plan of palliative care. That path would involve a much less invasive regime for ST. Dialysis would end and there would be no further attempts to resuscitate her in the event of a further major respiratory arrest such as occurred in March and July this year. Her treating clinicians are keenly aware of the need to involve ST as far as possible in how she would wish to be cared for and what steps might be taken to ensure that her last days or weeks of life were as comfortable and pain-free as possible. In preserving respect for her personal autonomy to make these choices, they have met with a fundamental obstacle which, on the case advanced by the Trust, is 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 relies on as rendering her incapacitous to make decisions for herself.
3. The Trust's case is that ST is "actively dying". It became clear during the course of the oral evidence I heard from Dr A, the consultant leading her care on the ITU, that this assessment does not mean that her death is necessarily imminent. She may have weeks or even months to live. The exact prognosis is uncertain. What is clear from clinical observation is that she has progressive respiratory failure with episodes of acute exacerbation resulting in breathlessness, distress and agitation. The current care

¹ For clarification, any reference in this judgment to 'expert' evidence is a reference to the medical/psychological evidence which I heard from ST's treating clinicians and others. There are no court-appointed experts in this case apart from Dr C, an independent expert instructed by the Trust pursuant to permission granted by Peel J on 26 July 2023.

plan is based upon the withdrawal of haemodialysis although ventilation will continue.

4. Despite all the difficulties which currently confront her, ST is able to communicate reasonably well with her doctors with assistance from her mother and, on occasion, speech therapists. Over the course of the last week she has engaged in two separate capacity assessments. I heard evidence from two consultant psychiatrists whose conclusions in relation to her capacity in both domains are set out in full written reports. In terms of communication, as in so much else, ST relies on the love and unquestioning devotion of her immediate family. Her mother has hardly left her bedside since her daughter's admission to hospital on 1 August 2022 after she suffered a respiratory arrest having tested positive for Covid. She joined the hearing today from the hospital. ST's brother and father were present in court. The family's support has been quite remarkable and, as all agree, has sustained ST through all the vicissitudes of the last few months. She has been described by those who know and love her as "a fighter". That is how she sees herself. At the heart of the issues in this case is what ST and her family perceive to be a ray of hope in the form of an experimental nucleoside treatment outside the United Kingdom which might offer her hope of an improved quality of life, albeit a life which is likely to end prematurely in terms of a normal life expectancy. She has told her doctors that she wants to do everything she can to extend her life. She said to Dr C, one of the psychiatrists who visited her last week, "*This is my wish. I want to die trying to live. We have to try everything*". Whilst she recognises that she may not benefit from further treatment, she is resistant to any attempt to move to a regime of palliative care because she wants to stay alive long enough to be able to travel to Canada or North America where there is at least the prospect that she may be accepted as part of a clinical trial.
5. No doubt through her unquestioning devotion to her daughter, her mother has expressed complete confidence that the treatment will work. Her brother is less confident but nevertheless supports his sister's wish to be given the chance of undergoing nucleoside therapy. Whilst ST herself told Dr C that she thought her chances of some recovery were no more than 50%, he told me that he had not interpreted that as a balanced or considered judgement on her part in relation to the likelihood of success but rather more an acceptance and acknowledgment that the treatment may not work. He reported that the whole family, including ST, see this as "the light in the tunnel". It is ST's clearly- expressed wish to stay alive long enough to reach that light and she opposes any attempt by her doctors to withdraw the life-supporting treatment which she is currently receiving prior to further enquiries being made as to her eligibility to join one of the trials. The family accepts that this potential treatment will be expensive. On ST's behalf her parents have issued an application whereby they seek to have the existing reporting restrictions lifted in order that they can publicise their daughter's situation in order to raise money for her treatment. That is not an issue which falls for determination today but it informs the preparations which they have been making to secure a place for ST on one of the

medical trials about which there is some limited evidence in the material before the court.

6. ST 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 the 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.
7. As matters stood when the case began, the two most recent capacity reports from Dr C and Dr D (both consultant psychiatrists who assessed ST in the days leading up to the hearing) suggested that she had capacity to make these choices for herself. The Trust, relying on the evidence of her treating clinicians, takes a different view. The Official Solicitor reserved her position until the conclusion of the evidence. She now offers qualified support to ST's position and accepts that, subject to any contrary view taken by the court, ST has capacity to conduct these proceedings through her own legal representatives and to make decisions in relation to her future medical treatment.
8. At the last directions hearing before Peel J on 26 July 2023, the court read a witness statement from Mr David Foster, a partner in a firm of solicitors which, in the light of the ongoing capacity assessments, had been requested to represent ST in this litigation. Although the circumstances of that firm's instruction are not clear from the statement, Mr Foster stated that, having met with ST the previous day, when he found to be "alert and conscious", he had agreed to represent her. He had obviously formed his own view that she was capable of giving him instructions. She had communicated to him that she understood that she had a mitochondrial disorder which was progressive and would likely lead to her death. She confirmed that she wished to continue treatment to give her "the best opportunity of life". When he raised the issue of experimental treatment in Canada she had given Mr Foster a "thumbs up" to indicate that this was her wish.
9. Present in court at the last hearing on 26 July were leading and junior counsel instructed by Mr Foster on ST's behalf. Notwithstanding the presence on that occasion of Mr Horne KC who was instructed by the Official Solicitor, Peel J allowed their application for permission to see all the papers and to attend, and participate in, this hearing. He confirmed the continuing appointment of the Official Solicitor as ST's litigation friend. Thus it was that Mr Garrido KC and Mr Quintavalle attended this hearing, cross-examined the medical witnesses and made final written submissions in relation to ST's capacity. On ST's behalf, they submit that she retains full capacity in both domains and that the legal presumption has not been displaced by any of the evidence relied on by the Trust. Thus the positions of the Official Solicitor and ST's own (informal) legal representatives are now more or less aligned. The Trust through its written closing submissions continues to maintain that she lacks capacity. The burden is on the Trust to establish its case that the interim position as at 13 April

2023 when this court recorded that “there is reason to believe that ST lacks capacity to conduct these proceedings” has not changed. My order made provision for an expert report in relation to both litigation capacity and capacity to consent to the medical treatment which then informed the Trust’s care plan, including life-sustaining treatment. The expert was also asked to consider whether ST met the criteria of a “vulnerable adult” thereby engaging the inherent jurisdiction of the court outside the parameters of the Mental Capacity Act 2005. All parties agree that this latter consideration is not an issue before the court today.

10. Before considering the body of medical and other evidence which informs the court’s decision in relation to capacity, I turn first to consider the law which I must apply. It is well-established and informed by a number of first instance and appellate authorities, many of which have been referred to in counsel’s skeleton arguments and closing submissions.

The Law

11. The general principles governing capacity are set out in s.1 of the Mental Capacity Act 2005 (“MCA”) in these terms:

“1. 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 made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.”

12. As to what is often referred to as “the diagnostic test” for capacity, s. 2 MCA states as follows:-

“2. People who lack capacity

- (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 a disturbance in the functioning of, the mind or brain.** [*emphasis provided*]

- (2) It does not matter whether the impairment or disturbance is permanent or temporary.
- (3) 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.
- (4) In proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.
- (5) [*No power under MCA exercisable in relation to a person under 16*].
- (6) ……….”

13. The second aspect of the test for capacity appears in s.3 of the Act (“the functional test”). It 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.”

14. Despite reference to the different aspects, or elements, of the statutory test, it is clear following the guidance given by the Supreme Court in *A Local Authority v JB* [2021] UKSC 52 that the core determinative provision within the statutory scheme for the assessment of whether a person lacks capacity is s. 2(1) MCA. In paragraph 65 of the court’s judgment, Lord Stephens said this:

“The remaining provisions of sections 2 and 3, including the specific elements within the decision-making process set out in section 3(1), are statutory descriptions and explanations which support the core provision in section 2(1). Those additional provisions do not establish a series of additional, freestanding tests of capacity. Section 2(1) is the single test, albeit that it falls to be interpreted by applying the more detailed description given around it in sections 2 and 3: see the judgment of McFarlane LJ in *York City Council v C* at paras 56 and 58-60.”

15. As the assessment of capacity is decision-specific, the court is required to identify the correct formulation of “the matter” in respect of which a decision is to be made. That, in turn, leads to a requirement to identify “the information relevant to the decision” under s. 3(1)(a) which includes information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision at all: s.3(4) and para 69 of *JB* (cited above). The court must for these purposes identify the information relevant to the decision within the specific factual context of the case with which it is dealing.

16. Paragraph 4.19 of the MCA Code of Practice emphasises the importance of potential consequences in the context of a person’s ability under s.3(1)(a) to understand information relevant to a decision. It provides that –

“If a decision could have serious or grave consequences, it is even more important that a person understands the information relevant to that decision.”

That requirement is subject to a “practical limit” on what needs to be envisaged as the “reasonably foreseeable consequences” of a decision within s. 3(4). As Lord Stephens said in *JB*, “to require a potentially incapacitous person to be capable of envisaging more consequences than persons of full capacity would derogate from personal autonomy” (see para 75). In a similar way, a person’s ability to use or weigh information relevant to the decision as part of the decision-making process “should not involve a refined analysis of the sort which does not typically inform the decision ... made by a person of full capacity”: (see para 77).

17. The court must therefore address two specific questions in order to determine the issue of capacity in this case. First, is ST unable to make decisions for herself in relation to (a) conducting litigation without the assistance of a formal litigation friend, and (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.
19. Capacity may fluctuate. For these purposes, the “material time” for the purposes of s. 2(1) is anchored to the time when a decision needs to be made. Given the Trust’s current application for an endorsement of its latest care plan which includes withdrawal of active medical intervention and a transition to palliative care, the decision in relation to capacity needs to be taken now. For that reason, I turn to consider the evidence which is available to the court.

The evidence

20. I have read a significant number of expert medical reports which chart the journey which ST has taken during her last twelve months in intensive care. Of particular relevance to the current application are four key reports.
21. In relation to diagnosis and prognosis, Dr F was identified by the Trust as a leading expert in the field of respiratory and critical care. He is based in London at a well-known teaching hospital and had previously given advice in May this year that ST could not be managed clinically other than in an intensive care setting. He was asked by Dr A to provide a second opinion concerning the Trust’s latest proposed care plan for ST. The request was made in mid-July this year following two acute episodes of hypoventilation as a consequence of apnoeic episodes over the course of four days.

22. Dr F expressed his concerns for ST in terms of these being an indicator that the progression of her mitochondrial disease was impacting on the motor output from her brainstem with a consequence that her “drive to breathe” was affected. He identified these episodes and the pneumonia which followed as “a poor prognostic sign in the context of invasive ventilation dependency”. His view was that she would not survive the ITU and, in terms of a clinical overview of the next steps, he supported the plan to limit ST’s care with a view to providing her with maximum comfort including the use, when required, of opiates and benzodiazepines. He paid tribute to the “phenomenal dedication and advocacy” which ST’s family had provided during the months she had spent in hospital as well as the comfort which their presence at her side had brought to ST.
23. Dr E is a leading expert in paediatric mitochondrial medicine and paediatric neurology. He specialises in the pathogenicity in mitochondrial disease and its management. On 11 April 2023, he identified ST’s disease as an extremely rare form of the disease which had been identified in only 100 cases on a worldwide basis. The mutation which occurs in ST’s mitochondrial DNA has affected the underlying energy currency in her cells. This, in turn, has led to the dysfunction and death of cells in a variety of her organs resulting in generalised muscle weakness, respiratory muscle insufficiency, and swallowing difficulties with aspiration pneumonia. Other organs such as the brain, kidney, and heart are typically affected with renal failure likely to be a direct consequence of the underlying cell mutations in the RRM2B gene.
24. In terms of available treatment options, Dr E has advised that “there is no cure for this or the vast majority of mitochondrial diseases and management is limited to symptomatic treatment”. In relation to nucleoside therapy, he has acknowledged its potential use as a treatment for RRM2B-related disease in that patients with a related but less complex condition appear to have derived some benefit in circumstances where the treatment has been given early in the course of their disease. In his view, “[e]ven if such treatment was available, it is highly likely that most benefit would be derived by those who are less severely affected and earlier in the course of their illness”. As to prognosis, he said this:-

“Unfortunately, I think that [ST’s] prognosis is extremely bleak. She has acquired an intolerable disease burden with generalised myopathy, respiratory failure, renal failure, severe gut dysmobility, deafness and severe swallowing problems. [She] is unable to be weaned from the ventilator because her respiratory muscles are too weak. They will remain weak and unable to support her breathing independently. In my experience of managing patients with mitochondrial disease, and more generally neurological disorders, I think it is evident that [ST] has entered a terminal phase of her illness. It is my opinion that the kindest and most clinically responsible course of action now would be to de-escalate the intensive care and make [ST] comfortable.”

25. Dr G, a consultant anaesthetist at the hospital where ST is being cared for, reported on 15 July this year that, whilst antibiotics had been effective in treating a recent episode of pneumonia, they would not be of any long-term medical benefit because of the current trajectory of her disease.
26. I heard oral evidence from four witnesses, each of whom had provided reports or witness statements to assist the court.

The expert evidence

Dr A

27. Dr A's latest of six statements was prepared on 3 August 2023 shortly before this hearing. It records his clinical findings and observations of ST during a meeting with ST and her mother three days earlier on 31 July. His view then was that "both were sincerely engaged with the process and there was no evidence of Mum imposing her ideas or of her affecting [ST's] responses at the time of our conversation". He found ST to be "alert and engaged throughout and was as bright as I have seen her over the past months". In terms of her general presentation:-

"She reported feeling better now than at the time of her recent respiratory compromise. She is oriented to time place and person. She recognised me, remembering my name and role and explained she knew about the court process."

28. Dr A had no problem communicating with ST with the assistance of her mother. His concerns around her capacity in relation to ongoing medical treatment and care revolve around her inability to understand that her breathing difficulties are the result of the progressive nature of her mitochondrial disease rather than the remaining effects of her illness from Covid almost a year ago. Further, he is concerned that she has failed to understand or accept the prognosis given to her by her doctors that she will soon die from this condition. ST told him that her belief in her ability to continue to survive was unshakeable. She is aware that she has been in an intensive treatment facility for almost a year and that there is nowhere in the United Kingdom where her life can be supported outside an ITU. She knows and accepts that she would need to be weaned off ventilatory support before she was able to live outside the unit but it remained her goal to try. Dr A was able to have a discussion with her about what would be involved in a further attempt but there would need to be a clear plan in place as to what would happen if that attempt failed. He felt he could not push her further about what that plan might look like. He visited her again the following day but she was too tired to speak with him having just completed a formal capacity assessment with Dr D.
29. The thrust of Dr A's oral evidence went to his assessment that ST has a "deeply seated misunderstanding" of her illness and her care needs. He believes that she is capable of understanding, retaining and weighing up information about her day-to-day

care needs and many of the more complex aspects of the care she is receiving. Where he believes she lacks these abilities is in relation to her treatment options in the event of her inevitable further deterioration or dying. Because she cannot contemplate an outcome which is inconsistent with her conviction that she can, and will, recover, she cannot address her mind to weighing up alternative options, including palliative care and what that might involve. She is passionate in her wish to undergo an assessment with a view to treatment in the United States and is prepared to undergo whatever it might take to achieve this end. In Dr A's opinion, whilst she clings to this hope of a better outcome involving her survival, she has closed her mind to the alternative of "greater comfort" or "less intrusive or painful treatment" which palliative care is likely to provide.

30. Dr A's dedication and devotion to the comfort and care of ST shone through his oral evidence as did the many years of professional expertise which he has brought to decisions about the treatment she has been receiving. He has sought and obtained second opinions from some of the most experienced experts in the field. He has listened carefully to the views of ST and her family. He has co-operated with their requests to provide medical details about her condition and treatment to those doctors in the United States and Canada who are conducting the research programmes and trials with which ST seeks to engage for assessment. She is aware that she may not be a suitable candidate and she knows that there are likely to be significant cost implications were she to be accepted for assessment and/or treatment. It is for that reason that she wishes the court to lift the current reporting restrictions in order that she and her family can embark on a fund-raising campaign. Dr A told me that he has made the family aware that he and his colleagues will assist the family in any way they can and provide as much information as is sought provided that the information is going to registered medical practitioners.
31. When the terms of s. 2(1) of the MCA 2005 were put to him, Dr A accepted that he could find no evidence of a psychological disturbance which was affecting the functioning of ST's mind or brain. He agreed that there was no evidence of brain damage as a result of the respiratory arrests she had experienced in recent weeks. His concern is that she is unable to weigh up the pros and cons of what he described as "a dignified death". As such he believes that she is suffering from a delusion which derives from a false reality in that she cannot contemplate her own death. He agreed when asked by Mr Garrido KC that the collective medical opinion about her prognosis had been wrong in the past and that it was very difficult to say what might happen next. Nonetheless he maintained that her survival was likely to be measured in days, weeks or maybe a month. He agreed during the course of his oral evidence that it was not impossible that she might survive until the "Fall season"² which is when one of the trials is likely to start. Although the precise definition of when this might be is not clear, I take it to mean sometime in October or November this year. His estimate of her survival until then is a one in four chance, or 25%. Dr A's

² [522]

immediate concern lay in the possibility of another precipitating event with no clear plan in place. In this event her treating team were at risk of “prolonging her dying”. He agreed that Dr C had reached a different conclusion about ST's understanding of her disease when he spoke with her but he himself had been unable to discern any acceptance on her part that she may die in the near future. When I asked him about the divergence in their professional views, he told me that ST may well have been prepared to share her views with Dr Cors as a result of his own discussion with her having prompted thoughts in her mind about dying.

32. Dr A was challenged during cross-examination by Mr Horne KC on behalf of the Official Solicitor about his view that ST was suffering from a form of delusion about her condition. He agreed that a hope to survive in a stable condition on the unit until receipt of an offer to travel to the United States or Canada for treatment whilst also recognising that alternative palliative treatment may be necessary in the event of a critical deterioration did not amount to a delusion. He said:

“My problem is simply the “if”. I can see no acceptance on her part that the most likely route is that she will destabilise and die. I have no wish to remove hope but my currency is “what is likely to happen?”. We need to write the menu for her to choose. We need to offer treatments that are appropriate and available.”

33. He continues to regard the position taken by ST and her family as an illegitimate disregard of the facts including the likelihood of benefit from the proposed treatment options abroad. In this view, he relies predominantly on the professional opinion of Dr E and his own reading of the literature on nucleoside treatment. He described those benefits as “vanishingly small”. He confirmed that the hospital was willing to do everything possible to maintain ST's stability up to the point where the court reached a decision in relation to her capacity to make her own decisions in relation to future medical treatment. In the event of a determination that she lacked capacity, and subject to any ‘best interests’ decisions taken by the court, the proposed way forward was for palliative care only as set out in the latest treatment plan. He stressed that it was important that the hospital had a time limit on how long the family with ST should be permitted to explore assessment/treatment options outside the United Kingdom. In the event of a further life-threatening event in the meantime, the Trust proposed to follow the current plan.

Dr B

34. Dr B, a consultant in intensive care medicine and anaesthesia, provided a witness statement which was relied on by the Trust to rebut any suggestion by ST and her family that the treatment she had been receiving was not necessarily appropriate and/or in her best interests. The focus of this statement was on the size of the tracheostomy tube which had been inserted in May this year when a previous tube was displaced. Both ST and her parents had complained that the use of a smaller tube as a replacement had increased her breathing difficulties. Dr B's evidence set out the

‘pros and cons’ of further surgical intervention and the difficulties which her treating team had encountered in weaning ST from her mechanical ventilation.

35. He agreed with Dr A’s assessment that ST had a 25% chance of survival until October although he told me that it was almost impossible to predict when she might die given her survival to date after a year in the ITU. There had been no further input from Dr E since his email in April, some four months earlier. That email had envisaged a move to palliative care and a withdrawal of active medical intervention at that stage. In answers to questions from ST’s family, Dr B told me that the symptoms which ST was experiencing had been present from December last year on her admission to hospital. They had become worse as a result of the progress of the mitochondrial disease which had weakened her respiratory muscles. She was also experiencing the effects of having been artificially ventilated for the best part of twelve months.

Dr D

36. Dr D is the Liaison Psychiatrist at the hospital where ST is being cared for. He has seen ST on a number of occasions since her admission to hospital. He confirmed during his oral evidence that he had seen her six or seven times between December 2022 and July this year. Thus far in August he has seen her on another four occasions and he therefore knows her well. He has produced three reports to date. The first was written following her admission to hospital on 16 December 2022. At no time during her year-long admission has he been asked to treat her for any underlying medical condition. He, with the nurses and ITU consultants, accepted and supported her wish that her parents should be involved in her care. In April 2023 Dr D was asked to prepare a formal capacity assessment. He saw her on 14 April for these purposes when he was accompanied by a representative from the Official Solicitor’s legal department. Before completing his assessment he had a full briefing from Dr A and another of her treating consultants. I do not intend to set out the detail of that assessment which are reflected in his second report dated 18 April 2023 since it has been superseded by his latest report. Suffice it to say that Dr D found ST to be comfortable, smiling, alert and “in clear consciousness”. She knew how long she had been in ITU and was able to communicate clearly about the treatment she was receiving on the unit. She became agitated when he broached the topic of what might happen if her condition deteriorated. From his interaction with her on this occasion, Dr D concluded that ST’s “higher cognitive function was not impaired”. She knew that the prognosis of her doctors was that she would die but she did not agree with them. She did not have any difficulty in understanding the nature of her disease or the information given to her by her doctors but Dr D was not able to discuss the options should her condition become terminal because she would not accept that to be the case. He concluded his first report in this way:-

“I did not find [ST] to show any compromise in her capacity to engage in taking part in decision making process and agree or give valid consent.”

37. That said, he expressed a view that she was a vulnerable adult as a result of her complete reliance on the medical care she was receiving.

38. Dr D's third report is reflected in a letter written on 5 August 2023 following a further capacity assessment undertaken at the end of last week. In its essential terms, he reported that:-

- (i) ST looked "bright, washed and nicely tucked in";
- (ii) she recognised Dr D and was relaxed and able to speak/mouth her words because she was not using her speaking valve;
- (iii) she was patient in communicating her views and corrected Dr D a few times when he had misunderstood what she had said;
- (iv) she was alert, knew when he had failed to understand her and rephrased what she wished to say;
- (v) she was aware that Dr D had been asked to see her by the court to conduct an assessment of her capacity and she said she was "mentally strong", aware of the court procedure in which she was involved and that she was not worried about it;
- (vi) she was aware that the haemodialysis was going "as well as it can" and that she was dependent on it;
- (vii) she was clear that she wanted treatment and active treatment;
- (viii) she recognised that she could not say where she might be in six months' time but she needed the treatment to continue;
- (ix) she was aware that she now needed the support of both mechanical ventilation and dialysis although she wished she could be without that level of support as she had been in the past;
- (x) she wanted to know why she was being subjected to assessment by different doctors when Dr D had already reported on this issue. She appeared to find the number of assessments intrusive;
- (xi) she was able to regulate her emotions and thanked Dr D when he reassured her that he understood her frustration. She told him that she had lost trust in her doctors and their opinions of how she was to be treated.

39. In conclusion, Dr D found her to be "less tired, more communicative, engaging well". He discussed with ST her illness and current condition as she saw it. She expressed a wish to have further consultation with different doctors. On balance, he found her to

be “open to discussion and reflective and capable of listening, absorbing information given and form[ing] her opinion”.

40. During the course of his oral evidence, Dr D confirmed that he found no signs or evidence of mental illness or any impairment of ST’s mind or brain. He agreed with the opinions expressed by Dr C having received and read his latest report on Monday of this week.
41. He was challenged on this view by Mr Sachdeva KC on behalf of the Trust. It was a robust challenge which flowed from a number of detailed and insightful questions. Dr D remained clear in his evidence that, despite her many physical limitations and the stress of her long stay on the ITU unit, ST did not lack capacity to make her own decisions in relation to her medical treatment. He clarified that her statement to him that she had been very ill but was not ill now was said in the context of a discussion about the extent to which she had recovered from her previous episode of pneumonia. Her current condition was her lived reality and she was able to recognise that she had made a recovery from what had been a serious deterioration in her condition. In terms of the current disagreement with her doctors, her belief was that she would not die “very soon”. (*“What she meant is that she is not going to die now. She meant that she was not a dying patient.”*) She had a clear understanding that she had lived with her condition for a very long time. She knew that it was a mitochondrial disease and a progressive illness and she was aware that there was no existing medical treatment which would reverse her condition or her current symptomatic presentation. She recognised there had been a deterioration in her underlying condition but she wanted ongoing treatment for underlying infections because it was her wish and her hope to engage in other options for her care. She did not trust the opinions expressed by her doctors because it was her view that the reason why her condition was changing was not a result of the progression of her disease but the means by which her doctors were addressing those changes in her presentation.
42. Dr D’s expert view was that she was in denial about the imminence of her death as expressed by the doctors despite the reality of being surrounded by the machines without which she knew she would not be alive. He told me that she had a very strong view that “she would come through one day”. That view was informed to an extent by both her religious faith and the love and support of her family. He described this not as a “false belief” but as a “different opinion” although he agreed when asked by Mr Sachdeva KC that she was wrong in her belief that her condition had not progressed. Whilst she knew her condition was progressive, she was clear that she did not wish to be put on a path to palliative care and thereby be deprived of an opportunity for hope. Of her capacity to consent to palliative care, Dr D’s view was that she had a different view of what this option meant. In her view, she would simply be left to die albeit with medical support for that process. She was quite clear in her view that she did not want this. In expressing these views, Dr D said that these were not fixed or delusional views. Rather they had been shaped by the medical

advice she had received both from her own doctors and from information about possible overseas trials. Above all, they were shaped and informed by a wish to stay alive for as long as possible. She understands that there is no further treatment available to her in this country and she further understand that what may be on offer elsewhere is experimental treatment and not a cure.

43. When questioned by Mr Horne KC On behalf of the Official Solicitor, Dr D confirmed that ST understands clearly that if she does not receive treatment, it will end her life at some point in the future. He confirmed that in his view she does not fail the functional test under the MCA 2005 because he could find no impairment in the functioning of her brain or mind.

Dr C

44. This was an opinion shared by Dr C, a consultant psychiatrist with over 25 years' experience who was instructed by the Trust to undertake a second assessment of ST's capacity. His first report in April 2023 had reached no specific conclusions because ST was unwilling to engage with him at the time. He visited her in hospital for the purposes of preparing his second report on 4 August 2023. For these purposes he had available to him all the material which is now before the court save for Dr D's most recent report. It is a lengthy and thorough assessment which sets out the entire background to ST's admission into hospital and the treatment she had received throughout her long stay there. It includes all the information he had collected from speaking to Dr A, including his views that (i) she has capacity for almost every decision apart from how to manage the inevitable deterioration in her respiratory capacity, and (ii) she is very vulnerable as a result of not having had the opportunity as a result of her illness to transition to adulthood. The report reflects the lengthy conversation which Dr C had with ST's family, including the progress which they were making in exploring the possibility of nucleoside therapy.
45. His interview with ST lasted just under two hours. The family apologised for not having engaged with him on his previous visit when they explained they had not been warned of his visit. Dr C saw no evidence of the family seeking to influence ST's views. They had an opportunity to express their views but allowed her to express what she wished to say without interrupting. Of the options now under active consideration, Dr C was updated on all three, two in the United States and one in Canada. Both ST and the family believed that, with appropriate arrangements, ST would be well enough to travel by air ambulance to one of these destinations. In relation to the potential success of nucleoside therapy, ST had been fully engaged in the discussion. She told Dr C that she "wanted to die trying to live". She was quite sure that everything must be tried before she would accept the inevitability of her death. In circumstances where each individual with mitochondrial disease had a different profile, both she and the family believed that there was at least a chance that other doctors with more experience of the disease might offer her some hope although their views differed as to the likely prospects of success. ST herself appeared to

recognise that there was an equal prospect of failure as success but she was clear that she should be enabled to take that risk.

46. ST was willing to engage with Dr C about what might be involved in a decision to move to palliative care and its likely component elements. In relation to the administration of morphine if she experienced problems breathing as had happened in the past, ST said that she did not like morphine because it was her wish to remain conscious. She was able to describe having had morphine for pain control after a previous laparotomy and she accepted that it was the right decision at that time. However, she was likely to reject the regular administration of the drug because of her wish to remain conscious and to see her mother at her bedside. She expressed a preference for oral paracetamol if she required pain relief in the future. In relation to concerns about the size of her tracheostomy, she appreciated the risks of surgical replacement and the doctors' concerns that she "might die" were a further procedure to be carried out. That was a risk she was prepared to take since she did not want to experience repeated infections. She also wished to be treated with intravenous antibiotics were her condition to deteriorate despite the views expressed by Dr G.
47. When asked about the prospects of being able to breathe without the support of the mechanical ventilator, ST told Dr C that she could not say whether this might be possible but this was her wish. (*"I want to die trying."*) She recognised that there was little prospect of a kidney transplant unless the nucleoside therapy was successful in securing an improvement in her condition and she was prepared to put up with the ongoing discomfort of dialysis in order to survive and avoid the alternative option of palliative care.
48. In relation to the ongoing litigation, she was aware that the Official Solicitor had been appointed to represent her best interests although she did not believe that she was fighting hard enough to support her wish to engage with nucleoside therapy. She felt that the Official Solicitor did not know her as a person and she was concerned that she might be too willing to compromise. She understood that Mr Foster had been instructed as an independent representative to advance her views to the court (*"He is going to fight for me."*) She was aware that "the Judge would make the final decision" in relation to her case.
49. Dr C has reached a conclusion that ST has capacity to make decisions about her care and medical treatment and that she has litigation capacity.
50. He considers that she does not meet all the aspects of the functional test because:-
 - (i) She does not *understand* sufficient aspects of her illness to meet the functional test of understanding. In particular, she does not understand she has progressive respiratory failure as a direct result of the progress of her mitochondrial disease for which there is no meaningful prospect of treatment. She has a fixed belief that her continuing dependency on

mechanical ventilation is the result of the effects from long Covid and the infections to which she has succumbed rather than the inevitable progression of her disease with the impact it has on increasing respiratory muscle weakness. He described that in his oral evidence as a fixed and false belief.

- (ii) There is no evidence that she has a problem with *retention*, or that her brain has been adversely affected by her disease or by recent respiratory arrests.
- (iii) She is *unable to weigh up* the consequences of decisions that she makes with regard to treatment since she believes that there is at least a prospect of recovery if she receives nucleoside treatment. In this context, she does not accept the opinion of her doctors with regard to prognosis and believes that, at some point, she may be able to breathe without the support of the ventilator.

51. Despite the insight which she has shown in relation to aspects of her care and treatment, Dr C's view is that her inability to contemplate "a 0% chance of recovery" impacts on her ability to weigh any decisions she makes about active treatment versus palliative care. As a consequence of the above, she does not meet all four elements of the functional test.

52. In terms of whether the failure to meet the functional test of test of capacity arises because of an impairment in or disturbance of the mind or brain, Dr C has concluded that there is no causal link or connection. He does not consider that ST has a mental illness which can be diagnosed using one of the standard classification procedures, although he has borne in mind in reaching his conclusions that there does not have to be a psychiatric diagnosis to support the possibility of impairment.

53. In his view, ST's belief, shared by her family, in the possibility that nucleoside therapy may provide some benefit is not likely to result, on the balance of probabilities, from a delusion or to be a symptom of an impaired mind. Rather, it results from the close relationship which she has with her family and their shared belief that there is a prospect for recovery. He is also of the view that her disagreement with the collective view of her treating clinicians does not flow from any paranoia. Rather, it flows from her own and her family's views that a move to palliative care is not in her best interests. In these circumstances there is no mental illness or impairment of mind but rather a disagreement with the doctors. In summary, Dr C's opinion is that ST's failure to understand the nature of her illness and her consequent ability to weigh up the facts in a decision-making process is not because of an impairment of mind but rather the result of the shared beliefs that she holds with her family.

54. In terms of litigation capacity, Dr C concludes that ST has capacity to litigate because she meets all four functional tests under s. 2(1) MCA 2005 and, in particular, is able to weigh up decisions which need to be taken within the ongoing court proceedings. He gave as an example her ability to weigh up the pros and cons of having her own independent solicitor in circumstances where she did not believe that the Official Solicitor was advancing a sufficiently robust case on her behalf.
55. During the course of cross-examination, Dr C was asked further questions about his opinion that ST's beliefs are anchored to the beliefs which she shares with her family. 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 C had formed a view that in circumstances where the three most important people in ST'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 A had expressed the prognosis for ST in an earlier statement as one where she had only "hours or days" to live, and where ST 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 C 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.
57. When I explored these aspects of his evidence with him at the end of his cross-examination, he said this to me:-
- "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."
58. The only other medical evidence before the court is that of a Court of Protection visitor who attended at the hospital on 20 May 2023 for the purposes of assessing whether ST had had capacity to execute a lasting power of attorney in November last year, the month before her admission to hospital. That LPA related to decisions in

relation to property and affairs and health and welfare. Peel J made a third-party disclosure order against the Office of the Public Guardian requiring the notes from that meeting to be disclosed into these proceedings. That order has yet to be complied with and I find it difficult to attach any particular weight or relevance to the views expressed in the assessment undertaken by the Court of Protection visitor. To the extent that Mr Garrido KC and Mr Quintavalle seek to persuade me to contrary (paragraph 13 of their closing submissions), I reject their submission. It is not possible in my judgment to consider any professional, or other, view in relation to capacity unless it is underpinned by a full understanding of the circumstances in which it was expressed and/or the information which was made available at that point in time to the assessor.

Counsel's submissions

59. On behalf of the Trust, Mr Sachdeva KC submits that it is a fundamental prerequisite in terms of the test for capacity that if a person is to understand, use and weigh relevant information, that information must be believed by the person who performs that exercise. ST's lack of belief in the information she is being given by her treating clinicians leads inexorably to her failing the functional test. He submits that Dr D's failure to engage with the salient questions under s.2 MCA in the context of the functional test mean that the court can only attach limited weight to his views.
60. In terms of the diagnostic test, he submits that, as was made clear in *North Bristol NHS Trust v R* (above), no formal medical diagnosis is required for the purposes of the statutory test. He points to the fact that each of Dr A, Dr B and Dr C had reached a clear view that ST's views regarding prognosis and the prospects of success in relation to the proposed treatment were both false and fixed. Where they differed was whether those beliefs were adequately explained by her social or cultural background and hence, whether they could properly be said to be delusional. He submits that none of the reasons advanced by Dr C for preferring to see her views as understandable in the context of her family's views - rather than as an impairment in the functioning of her mind - is sustainable in the light of the body of evidence which is now before the court.
61. The Official Solicitor's final position is that, on balance, ST has capacity to make her own decisions about the litigation and the medical treatment in issue. On the basis that the decision for ST as to whether or not to consent to the limitations of treatment within the palliative care treatment plan is "the matter" which this court has to determine, she submits through Mr Horne KC that the "information relevant to the decision" is the following:-
 - (i) she has mitochondrial depletion syndrome (RRM2B) which is rare;
 - (ii) the disorder is progressive and is the cause, rather than long-Covid, for her widespread clinical deterioration since her admission to the ITU in

December 2022;

- (iii) the disorder is responsible for the deterioration in her respiratory function;
- (iv) any small insult may cause potentially fatal clinical instability and the treating team suggest that her survival is measured in days or weeks;
- (v) there may be a possibility for her to undergo nucleoside therapy in North America but –
 - she has not been accepted for that experimental treatment;
 - there will be significant practical difficulties before she could receive such treatment, including both fund-raising and the logistics of travel;
 - there is no evidence before the court as to whether such therapy would produce any benefit for her, and still less hope that it would enable her to breathe independently without support from a mechanical ventilator and/or to undergo a renal transplant;
- (vi) the clinical team at the Trust would not stand in the way of a transfer to North America.

62. These aspects of the relevant medical information coincide more or less with those which I have outlined generally in paragraph 18 of my judgment and represent the broad consensus of what is required in this case.

63. In terms of the functional test which the court must consider under s. 3 of the MCA, the Official Solicitor agrees with the submissions made on behalf of the Trust that the court must exercise care in determining what weight to attach to Dr D's first and second reports. He did not feel able to put to ST the clinicians' views as to her current condition or capacity. She was not asked for the purposes of his formal capacity assessment what her view was about prognosis and treatment if she could not travel to North America for treatment. Because of the number of times which he has seen her over an extended period of time, the Official Solicitor accepts that more weight can be given to his view that she was not suffering, and does not suffer from a recognised psychiatric or psychological disorder.

64. In terms of Dr C's evidence, the Official Solicitor submits that it was both thorough and reflective. Although his second report set out his conclusion that she was unable to weigh the consequences of her decision in relation to the Trust's treatment plan because she was fundamentally unable to accept that her condition was progressive, his oral evidence was more nuanced. The two dominant factors which she did not believe (and was therefore unable to weigh) were (i) the fact that her prognosis was as

bleak as the doctors have told her absent nucleoside therapy, and (ii) there is no realistic prospect of nucleoside therapy improving her condition to the point where she can be weaned off a ventilator. The Official Solicitor seeks to persuade the court that neither of these facts should lead inevitably to a conclusion that she fails the functional test.

65. First, there is no evidence that ST is now in denial about the fact that her overall condition is progressive. The evidence from both Dr D and her brother was that she was aware that her condition involved the possibility of death. Dr C reflected ST's expressed wish that she wanted "to die trying to live" and that no option must be left unexplored in that endeavour ("*We have to try everything*"). In this context it is submitted that the court must consider whether the views she is expressing, insofar as they do not coincide with those of her treating clinicians, mean that her ability to make a decision in this context is only "impaired" thereby falling below the threshold of what is required for the purposes of s. 3 MCA.
66. In terms of the functional test, the Official Solicitor accepts that it is a more difficult exercise to determine whether she fails the functional test because of an inability to understand, use or weigh the information about the potential benefits of nucleoside therapy. It is accepted in this context that she appears unable to understand what Dr E described as the "vanishingly small" prospects of her receiving such treatment at all and/or any benefits which might be achieved as a result. In this context the Official Solicitor accepts that Dr E's evidence is the most authoritative information which the court has in relation to the prospects of nucleoside therapy. Whilst he has not seen ST and specialises in paediatric rather than adult neurology, the Official Solicitor does not seek to argue that his views and opinions should carry less weight as a result.
67. The concern of the Official Solicitor in this context lies in where the boundary should be drawn between an unwise and an incapacitous decision. It is submitted on behalf of ST that the court must take account of the understandable human emotion of hope even if that hope is forlorn in the dire circumstances in which ST finds herself. In these circumstances the Official Solicitor submits that the court could use the presumption of capacity to conclude that ST's ability to undertake the relevant exercise, whilst impaired, does not reach the threshold established in s. 2(1) MCA.
68. In terms of litigation capacity, the Official Solicitor accepts on the facts of this case that the court is unlikely to find that ST retains litigation capacity whilst lacking subject matter capacity.
69. The final submissions of Mr Garrido KC and Mr Quintavalle on behalf of ST focus on the issue of whether there is evidence available to this court which supports a finding that there is an impairment such as to engage the provisions of the MCA at all. They submit that the Trust has conflated the requirement to identify an "impairment" with the two-stage process identified in paragraphs 67 and 78 of *JB*. Both Dr D and Dr C agree that ST has no diagnosed disorder of the mind. Since the medical expertise of

both Dr A and Dr B does not lie in matters of psychiatry, it is submitted on ST's behalf that the court should not put any, or any significant, weight on the views expressed by those treating clinicians which falls outside their respective areas of expertise. If the court does find that there was a disorder of the mind such as to engage the provisions of the MCA, Mr Garrido KC and Mr Quintavalle submit that lack of capacity would only be established if all practical steps had been taken to assist ST and help her to make a decision : s. 2(3) MCA. On a proper analysis they submit that the court does not have evidence of ST having failed to make a decision. The Trust's submissions are directed instead to the nature of the decision she has chosen to make and this course is impermissible insofar as it represents an "unwise" decision: s.2(4).

70. Finally, they submit that ST's decision-making ability cannot be impugned in circumstances where –

- (i) at least two hospitals outside the jurisdiction of England and Wales appear to be willing to consider her as a candidate for treatment or, at least, have not ruled her out;
- (ii) her own treating clinicians, who lack experience in the treatment of mitochondrial disease, have repeatedly and inaccurately anticipated her imminent death;
- (iii) Dr E's opinion needs to be treated with caution because he does not have the relevant experience in treating adults who suffer from mitochondrial disease and has not seen or spoken with ST;
- (iv) her own clinicians have not become involved in direct discussions with the North American treatment centres who have been approached; and
- (v) the rare nature of her condition and the uncertainty which surrounds her prognosis must leave the court in doubt as to her alleged incapacity to decide on her own medical treatment.

71. In terms of litigation capacity, Mr Garrido KC and Mr Quintavalle accept that this issue is indistinguishable from the question over whether she has capacity over decisions relating to her health and welfare. They agree that, in this case on its particular facts, a decision in relation to litigation capacity will follow a decision in relation to her ability to consent to a particular proposed course of medical treatment. In relation to both, they urge upon this court a finding that ST has full capacity in both domains.

Discussion and analysis: my conclusions

72. It is important to emphasise at this point that my judgment at the conclusion of this hearing is limited in terms of its scope. At the last hearing before Peel J on 26 July 2023, it was agreed by all parties that the issue of ST's capacity to litigate and to consent to medical treatment, including the palliative care plan dated 20 July 2023, should be determined as a preliminary issue. I am not asked to determine whether the treatment set out in the palliative care plan is in ST's best interests. I am not authorising her treating clinicians to proceed with that plan. I am not determining whether it is in ST's best interests to travel to North America or Canada to participate in a trial of nucleoside therapy. I am not at this stage asked to decide whether the terms of the existing transparency order should be varied so as to permit the family to publicise aspects of this case with a view to fund-raising for these purposes.
73. In terms of the family's approach to this litigation, it is important to stress at the outset that they have been driven in all they have done by the love they have for their daughter and sister. They wish above all else to keep her alive and well enough to engage with whatever therapies might become available. I have no doubt at all that ST has survived the significant challenges of the last twelve months as a result of the overwhelming love and support she has received from her family. Despite her belief that there are aspects of her treatment about which the doctors have been wrong, it is equally clear that her clinical team and the nurses who have looked after her have provided an exceptional level of care. It is that care together with ST's own passion for life and living which have kept her alive to this point in time. It is clear to me that ST and her family accept that her hold on life is fragile although they reject the pessimistic prognosis they have been given. There is an urgency in what they say to this court. Her brother addressed the court during the hearing on behalf of the family. He told me that ST is currently fighting for her life. She wants to live and wishes to enter a treatment trial even if that trial is experimental with no guarantee of success. He told me that the family is aware that her disease is progressive but her condition is very rare and the available data is sparse. He said that ST has watched patients on the ITU die around her every week. She recognises the possibility of her own death and is prepared for that but, to use her own words, "she wishes to die trying to live".
74. These are powerful words and I would wish the family know that I have the utmost respect for their views and those currently being expressed by ST. My role for the purposes of this judgment is to make a determination in relation to capacity based upon all the evidence I have heard and read in the context of both the statutory framework provided by the MCA 2005 and existing case law.
75. In terms of framing the decision which is the subject of the capacity assessment I am making, I start with both the legal presumption of capacity and the need to adopt a patient-centred approach. That approach must be conducted in the context of an objective and measured view of the medical and other evidence before the court.
76. I have set out in paragraphs 18 and 61 of this judgment the scope of the information which is relevant to the decision for the purposes of s.2(1) of MCA 2005. The parties

agree that ST has capacity to make a significant number of decisions for herself in relation to her care. Dr A accepted that to be the case. At the heart of the current dispute in relation to capacity is ST's ability to use and weigh the information she has 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.

77. Important and fundamental aspects of the information which is relevant to any decision she makes are the following:-

- (i) the nature of her disease and the fact that her disease is responsible for the deterioration in her respiratory condition;
- (ii) the assessment of her medical team as to prognosis;
- (iii) the available options in terms of active treatment including the likelihood of that treatment being available and its chances of success;
- (iv) the fact that a small insult arising in the course of her care or management or the further development of her disease (such as another respiratory arrest) may cause potentially fatal clinical instability.

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.

79. In *Re MB (Medical Treatment)* [1997] 2 FLR 426, Butler-Sloss LJ said this at page 437 in a case concerning capacity to consent to medical treatment:-

“A person lacks capacity if some impairment or disturbance of mental functioning renders that person unable to make a decision whether to consent to or refuse treatment. That inability to make a decision will occur when:

- (a) the patient is unable to comprehend and retain information which is material to the decision, especially 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.”

80. In *Local Authority X v MM* [2007] EWHC 2003 (Fam)³, Munby J confirmed that there was no relevant distinction between the test as formulated in *Re MB* and that set out in s. 3(1) of the MCA 2005 (see paragraph 80).

81. At paragraph 81, Munby J said this:

“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.” [*emphasis provided*]

82. That approach has been followed in a number of first instance decisions including *Leicester City Council v MPZ* [2019] EWCOP 64. That case involved a young woman (P) with learning disabilities and personality disorders in the context of decisions concerning both her litigation capacity and the arrangements for her residence, care and contact with others. The approach developed by Munby J was thus applied in a different factual context but accepted and adopted by both the medical experts and the judge who held that the rejection by P of evidence which was objectively true prevented her from using the information effectively for the purposes of informed decision-making.

83. Whilst it is clear that the strict terms of the MCA 2005 omitted a ‘belief’ requirement from the wording of ss. 2 and 3, it is clear from *Local Authority X v MM* that the approach taken by Munby J subsumes the requirement for belief within the statutory limbs of understanding, using and weighing as part of the decision-making process. In this context, and in terms of a patient-centred approach, it is important in my judgment for the court to consider the extent to which the information provided to a person is capable of being established objectively as a “fact” or a “truth”. The less certain the fact or truth, the more careful the court must be when determining whether the presumption of capacity is rebutted.

84. In this case I accept that ST is aware of the nature of her disease in terms of it being a mitochondrial depletion syndrome which is rare. She knows that she is one of few people in the world to have the disease. I further accept that she knows the disease by its nature is progressive and she recognises that, at some point in the future, she may succumb to its effects and die. 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.

³ *MM* was a case decided under the inherent jurisdiction before MCA 2005 came fully into force.

85. As to the ‘truth’ or reliability of the information which ST is being given by her doctors, I am quite satisfied on any objective basis from the body of medical evidence before the court that it is the mitochondrial disease which is causing the progressive failure of her respiratory muscles and the general deterioration in her overall condition. It is not the residual after-effects of long-Covid as ST believes it to be.
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.
87. Because of the rarity of her disease, it appears that there are no experts in the field who have experience of successfully treating adult patients such as ST who are in the advanced, if not final, stages of progressive disease. In these circumstances Dr E’s evidence is likely to be the best available to this court. I do not accept that it carries less weight because he specialises in paediatric research and/or because he not met ST to assess her personally. He is acknowledged to be a leading expert in this field and it is clear from his evidence that he understand the pathology of ST’s underlying disease in all its elements. She is exhibiting many of the symptoms of advanced disease which he describes objectively in his email to Dr A. Nucleoside therapy is, as yet, untried and untested. It appears that the only research to date involving patient trials has been undertaken in the context of individuals with a different gene mutation. As Dr E states:
- “The quantities and ratio of bases necessary to attempt [to] treat RRM2B-related mitochondrial disease have not been determined and progress has been hampered by the lack of an appropriate animal model of disease. Even if such treatment was available, it is highly likely that most benefit would be derived by those who are less severely affected and earlier in the course of their illness.”
88. ST does not appear to meet either of these criteria. Further, from the evidence it appears that the option of treatment in Canada is not an immediate option because the trial has been paused as a result of funding constraints. None of the material disclosed by the family or the Trust in relation to potential treatment options in North America confirms that ST will be considered eligible and there is no evidence available at this point in time to contradict the evidence of Dr E as to the likely benefits to her. There

is no estimate of the cost of treatment or the ability of the family to procure funding by whatever means they can.

89. Against those exceptionally slim odds, a capacitous decision in relation to embarking on this treatment must surely encompass an understanding of what would be involved in making the transatlantic journey to North America. On the assumption that a place on a trial of treatment was available and funded, it is clear from Dr A's evidence that there would be very significant risk to ST in attempting the journey, including a risk to her life. Whilst she would need to be moved with the assistance of a mechanical ventilator, she would be disconnected from the haemodialysis on which she currently relies for survival. Dr A acknowledged that his hospital had been involved in arrangements for the transfer of patients from the battlefield in Afghanistan with serious life-threatening injuries. Nevertheless, it will be a complex and delicate exercise to ensure that any similar arrangements to transport ST overseas for treatment are as risk-free as they can be. As he told me, any small insults at this stage such as those which healthy individuals would shrug off without effect could potentially result in catastrophic consequences for ST.
90. In his opening position statement on behalf of the Official Solicitor, Mr Horne KC pointed out that neither the parents nor Moore Barlow LLP, who purport to act independently for ST, had served any medical evidence to rebut what he described as "the clinical reality" set out by the Trust. He described the suggestion that she could be transferred abroad for treatment as "fantastical" given her parlous clinical state.
91. I say this not in the context of anticipating in any way a best interests decision about this potential treatment but because it is information relevant to the decision which ST wishes to make in terms of her future treatment without interference from her doctors or the court. Because she does not fully understand the progressive effects of her disease and is unwilling or unable to believe the prognosis offered by her doctors, she regards treatment overseas as her only chance or option. On the basis of all the evidence before me, I cannot be satisfied that she has properly understood what might be involved in that course, even if it is available to her at some point in the future.
92. I am unable to accept Dr D's evidence that ST passes the functional test despite the conviction with which he gave his evidence when under challenge. Dr C accepts that she fails the functional test because the two dominant factors which she did not believe (and was therefore unable to weigh) were (i) the fact that her prognosis was as bleak as the doctors have told her absent nucleoside therapy, and (ii) there is no realistic prospect of nucleoside therapy improving her condition to the point where she can be weaned off a ventilator.
93. I agree with those conclusions. In my judgment the answer to the first question posed in *JB* (above) is that ST 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 ST'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.

94. In relation to the concerns raised by the Official Solicitor in this context, I can accept the proposition that an individual who expresses hope that they will survive, or even a belief based on that hope, does not, without more, become incapacitous simply because they disagree with the medical advice they are given. In my judgment in this case, as the evidence demonstrates, ST's fundamental distrust in, and refusal to accept, the information she is given by her doctors as to the likely timescales of her deterioration, do not simply operate to impair her ability to make a decision. They prevent her from understanding, using and weighing the information in the context of the options available to her in terms of future care planning. Dr A expressed himself to be entirely open to discussing these options with ST. Indeed, he saw it as an essential part of the care he was providing as her lead treating clinician. She was unwilling to engage with him at all on the subject because she does not trust the information he has given her. Dr D did not raise with ST the question of alternative options and what palliative care might look like in terms of an alternative. Dr C confirmed in his evidence that ST was unable to weigh up any decision about palliative care because she failed the functional test.
95. The next question which the court must determine is whether ST's inability to make a decision for herself is because of an impairment of, or a disturbance in the functioning of, her mind or brain (the diagnostic test). The preponderance of the clinical and expert evidence from Dr A, Dr B and Dr C is that ST's views regarding her prognosis and the prospects of treatment being successful were both false and fixed. As I have set out above, they may be false views but I do not necessarily regard them as fixed. At this point in time, ST is able to recognise the nature of her disease and that without treatment which is by its nature experimental, she will die and be deprived of a normal lifespan which any other 19 year old might expect to enjoy. 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.

96. In *North Bristol NHS Trust v R* [2023] EWCOP 5, MacDonald J stressed the importance of the question which the court must address in the context of the diagnostic test posed in s.2(1) MCA. The court does not ask whether the person's ability to make the decision in question is *impaired* by the impairment of, or disturbance in the functioning of, the mind or brain but rather whether the person is *rendered unable to make the decision* by reason thereof (see paragraph 41(v) and *Re: SB (A Patient: Capacity to Consent to Termination)* [2013] EWHC 1417 (COP) at [38]).
97. That issue is a question of fact for the court to determine. The wording of s.2(1) MCA itself does not require a formal diagnosis before the court can be satisfied as to whether an inability of a person to make a decision in relation to the matter in issue is because of an impairment of, or a disturbance in the functioning of, the mind or brain. This test is not further defined in the Act. As the court made clear in the *North Bristol NHS* case, to require a specific diagnosis would not only be undesirable, it would constrain the application of the Act. The court, instead, is fully entitled to have regard to the wide range of factors that may act in any individual case to impair functioning of the mind or brain and, most importantly, to the intricacies of the causal connection or nexus between lack of ability to take a decision and the impairment in question (see paragraph 47). There is thus no requirement for the court to be able to formulate precisely the underlying condition or conditions which constitute the impairment.
98. As to the nature of the impairment of, or disturbance in the functioning of, the mind or brain which prevents ST from understanding, using and weighing the information which she has been given, it is accepted that ST does not suffer from any recognised psychiatric or psychological illness. Dr C struggled to identify precisely how to 'label' ST'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.
99. I do not find it particularly helpful in this case to frame the enquiry in terms of whether or not ST is delusional. I am also not persuaded that any fixed belief she holds as to her ability to recover at least improved functioning if she is permitted to embark on nucleoside therapy is explained by her social or cultural background. ST is a young woman who experienced a traumatic emergency admission to hospital as a result of respiratory difficulties when she contracted Covid 19 at the end of last year. The progressive deterioration of her condition and her complete dependence on various forms of mechanical and medical interventions which have kept her alive since then over many, many months in a highly artificial and completely medicalised

environment are highly likely to have caused further trauma, as Dr C confirmed. Throughout, ST has expressed a wish to survive. She has suffered acute episodes of distress and anxiety when she has needed emergency medical interventions and sought reassurance from her mother when she thought she might be dying during one such intervention. She has needed morphine to relieve some of her more distressing symptoms. She has lived for many weeks, if not months, during which doctors have been telling her that she is in the final stages of her life, if not actively dying, a prospect she has refused to contemplate. It is hardly surprising in these circumstances in my judgment that she looks to those family members around her for support and reinforcement of her own views. Her mother has refused to contemplate anything other than that therapy will succeed and there can be little doubt that those views will have been communicated to ST.

100. ST told Dr A that her belief in her ability to survive her disease was “unshakeable”. He has characterised this as a “deeply seated misunderstanding of her illness and her care needs”. At present she is unable to contemplate an outcome which is inconsistent with her conviction that she can, and will recover. She cannot address her mind to weighing up alternative options, including palliative care and what that might mean for her. Dr D formed a clear view that ST was in denial over the imminence of her death. Whilst Dr C’s assessment provided some insight into what palliative care might look like (for example her wish to remain conscious and able to see her mother), he agreed that she has no insight into, or appreciation of, the entire body of medical opinion which supports the prognosis she has been given. He also believes that she has no realistic appreciation at all of the likely outcome of treatment. He has described her as a psychologically vulnerable young woman who has not been afforded the opportunity to transition into adulthood because of the toll which her illness has taken on her.
101. The question which I must answer in the light of this evidence is whether ST is thereby rendered *unable* to make a decision in relation to her medical care because of an impairment of, or disturbance in the functioning of, her mind or brain. In this context, there is potentially a wide range of factors which may act in this particular case to impair functioning. I have referred to some of them above. For these purposes it is sufficient if the court finds some form of psychological or other impairment which impacts on ST’s ability to take a decision. It is not necessary as a matter of law to attach to that impairment a specific diagnostic label such as that for which Dr C was searching.
102. I agree with Mr Sachdeva KC that all the evidence points to ST’s survival to date being the result in large measure of the increasingly intrusive, if not extreme, interventions which her clinicians have used to keep her alive. I have no doubt that ST’s personal resilience in the face of the odds presented to her and her strong wish to survive have contributed to the success of the efforts which her doctors and nurses have made to preserve her life. However, it is clear to me that ST has closed her mind

to the prospect that the medical prognosis she has been given may be sound. It may be that this is what she has needed to do to sustain her unshakeable belief in the likelihood she will recover. Mr Sachdeva KC seeks to characterise as irrational Dr C's view that ST's views are understandable in the circumstances in which she finds herself. On his case that same irrationality infects the family's and ST's views that there is a worthwhile chance of a cure when the overwhelming preponderance of the medical evidence points in the alternative direction.

103. In my judgment, and based upon the evidence which is now before the court, I find on the balance of probabilities that ST'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 C. 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 ST 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. The Official Solicitor submits that the Trust's reliance on the same beliefs which impair ST's decision-making ability under the first limb of the test in s.2(1) MCA to found the existence of an impairment under that section is circular and undermines the importance of the second question in s.2(1). In my judgment that is to misunderstand the Trust's position and the basis of my finding that, on the balance of probabilities, the impairment in ST's functioning has been established. 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 ST'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.

105. In the circumstances I do not see what further steps could be taken to help ST to make a decision and in these circumstances decisions as to her best interests in terms of future medical treatment must remain a matter for a Tier 3 judge sitting in the Court of Protection. These decisions, absent agreement between the parties, will include the family's proposal to continue to explore the option of experimental treatment outside the United Kingdom and their extant application to vary or discharge the terms of the existing reporting restrictions order.

Litigation capacity

106. Despite the view of Dr C and the position urged on me by Mr Garrido KC and Mr Quintavalle, I am satisfied that this is a case where ST lacks capacity to litigate without the assistance of a litigation friend. Capacity to litigate includes not only an understanding of the issues in the case but an ability to understand, use and weigh the arguments on the evidence so as to give instructions in relation to the arguments of other parties who may take an opposing position. Given my findings in relation to subject matter capacity, it is difficult to conceive of circumstances where ST might be said to have full litigation capacity but lack subject matter capacity. I am concerned about the lack of information in which Mr Foster of Moore & Barlow came to be instructed and whether the origin of that instruction was ST herself or her family. I offer no criticism of their involvement in this hearing. They attended at the invitation of the court in order that the court might have the benefit of full argument. In that respect, the attendance of Mr Garrido KC and Mr Quintavalle at this hearing has been of considerable assistance to the court.

107. Those are my findings in relation to capacity.

Order accordingly