



Neutral Citation Number: [2024] EWCOP 65 (T3)

Case No: COP20003709

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 31/10/2024

Before :

THE HONOURABLE MR JUSTICE HAYDEN

Between :

**Barnet, Enfield and Haringey
Mental Health NHS Trust**

Applicant

- and -

**(1) CC
(by her litigation friend, the Official Solicitor)**

(2) F

(3) M

Respondents

Adam Fullwood (instructed by **Bevan Brittan LLP**) for the **Applicant**
Fiona Paterson KC (instructed by **the Official Solicitor**) for the **First Respondent**
F and M appearing in person

Hearing dates: 30th and 31st October 2024

Approved Judgment
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This judgment was delivered in public but a transparency order is in force. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the protected party and members of their family must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Hayden :

1. This is an application concerning CC, who is a 21-year-old woman, who lives at home with her family. She is the 4th of 8 children, all of whom are girls. CC describes her family as being ultra-orthodox Jewish. In her childhood, moving into adolescence, she found the rules and strictures of her community were not ones that she could adhere to. Her temperament, personality, and as it later transpired, her autism spectrum disorder (ASD), rendered her unable to conform with an ultra-orthodox life. I think it likely, from the evidence that I have listened to and read, that this was a source of sadness to her parents, and in her own way, to her. However, the family has been able to negotiate this, both understanding and accommodating it. They recognise that CC is simply who she is. The wider community has followed the lead of the family, and they have been an important part of CC's support structure.
2. It is clear to me that CC is a young woman who is effervescent with talent, energy, and intellectual ability. It is something of an understatement to say that she does not 'suffer fools gladly', to use the phrase that many have used when talking about her. She has great confidence in her own abilities, though, it must be said, she is somewhat dismissive of those not bestowed with her talents.
3. CC evaluates others, she tells me, by 2 criteria, namely that they "*should have a great brain and a great heart*". Though that might sound opinionated, it reflects an inflexibility of thinking style in the sphere of human interaction and is a facet of her ASD. CC herself certainly meets her own criteria. She has both a great brain and a great heart. Her intellect is in abundant display and needs no further comment from me, but her warmth, empathy, and compassion are equally clear. Everybody who has spoken about CC has commented upon her enthusiasm for, and skill in helping and caring for people with disabilities of some kind, particularly youngsters with learning disabilities. She is modest when she talks about those she has cared for, but she is also rightly proud of the support she has been able to give. She has received a number of warm tributes from the families of those she has been able to help.

4. This case came before me because the Applicant Trust were seeking declarations as to whether CC had capacity to conduct these proceedings, and to make decisions concerning her medication and treatment. On 22nd October 2024, I granted leave for the instruction of an independent psychiatrist to assist the Court on these issues. Dr Matthew Cahill was instructed. Dr Cahill is a consultant psychiatrist specialising in Eating Disorders. He is the Clinical Director for the Cheshire and Wirral Partnership Eating Disorder Service, recognised as a Regional Specialist Unit, treating the most severe cases of anorexia nervosa, across the Northwest of England, North Wales, and Isle of Man. Dr Cahill is the clinical lead for the Northwest Adult Eating Disorders lead provider collaborative. He is also a member of the Royal College of Psychiatrists Faculty of Eating Disorders Executive Board. He has been working, for over 9 years, in the medico-legal field and has acted as an expert in a number of complex and high-profile Court of Protection cases relating to disordered eating. He was instructed in the case of *Re WA* [2020] EWCOP 37. I mention this case because the family have read it carefully and see in it some parallels with CC's situation.

5. CC's treating clinicians had concluded that she was unable to make decisions concerning her medical treatment due to her overwhelming fear and distress, generated by her anorexia nervosa and compounded by her autism and depressive disorder. They concluded that she could not weigh the relevant information:

“[CC]'s profound fear of weight gain interferes with her ability to weigh up benefits of increased nutrition to support weight restoration against the significant adverse impacts of remaining in a state of severe malnutrition. This has the consequence, that although [CC] states that she wishes to recover from her eating disorder, she is not able to contemplate accepting the additional nutrition required in order to move forward with her recovery, due to her fear of weight gain, and her distress at the point of accepting nutrition.

Furthermore, the demand avoidance states interfere with her ability to accept medical treatment for complications of her eating disorder [e.g. hypokalaemia or acute kidney injury] and

when she is in such a state of demand avoidance, she is not able to adequately weigh up the benefits of such treatment against the significant risk of refusing treatment.” [66]

6. Later, CC’s capacity to weigh relevant information is directly confronted:

“Weigh information: [CC] is able to recognise the risks of severe malnutrition on her physical health, including the risk of collapse/sudden death. However during an inpatient admission the emotional distress that [CC] experiences on an inpatient unit is such that it interferes with [CC]’s ability to participate in a collaborative treatment plan that supports weight restoration. During inpatient admissions the overwhelming nature of [CC]’s demand avoidance state interferes with [CC]’s ability to weigh up information, such that she enters behavioural states that move her away from her stated goal of wishing [in the longer term] to recover from her eating disorder. In such a state [CC] is compelled to following her own set of restrictions [eg by participating in total nutritional restriction] that it becomes difficult for [CC] to see the “bigger picture” and meaningfully weigh up the necessary information in order to construct a workable collaborative inpatient treatment plan.” [95]

7. Accordingly, there was significant evidence that pointed to CC lacking capacity. Dr Cahill also agreed. It is important that I emphasise that Dr Cahill was instructed late in the day and was afforded very little time to absorb the background. It was necessary to move at pace because CC’s physical health is in a parlous state. Dr Cahill’s mastery of the background history, in such a short time, is impressive. He emphasises that the medical notes of this case require to be read particularly carefully and in full. From February this year to the present, CC has had episodes of complete food restriction, causing sudden deterioration in weight, vital signs, and blood chemistry. She has also, at times, refused her medication; she has been self-harming by head-banging and cutting. There has been stockpiling of medication and intentional overdoses. She is at

present severely malnourished with frailty, weakness, low energy levels, difficulties with concentration, and irritability. She struggles to walk even for short distances. She has episodes of acute kidney injury and hypokalaemia. She describes chronic pain.

8. In addition to the above, CC is low in mood with ongoing thoughts of suicide. She feels hopeless that it will ever be possible for her to make progress towards recovery. She expresses a wish to die but also, with some frequency, an equally strong will to live. Her prognosis is poor, in the view of her treating clinician. As well as her low weight, he identifies a life expectancy “*not beyond 6 months*”. The treating team outlined 5 potential proposals:

*“**Proposal 1** - continued voluntary admission where [CC] attends for inadequate nutritional support via the PEG tube and that a Mental Health Act is not pursued even if she is at immediate risk. They outline the potential advantages and disadvantages of this proposal.*

***Proposal 2** – admission under Section 3 of the Mental Health Act in order to offer PEG feed meal plan on the ward and potassium replacement against her wishes. Again they outline the potential advantages and disadvantages of this proposal.*

***Proposal 3** – to employ an agency nurse in outpatients to support [CC’s Mother] to administer PEG feed. This would be a Monday to Friday arrangement whereby a nurse could administer the PEG feed in the community.*

***Proposal 4** – CC will attend the outpatients three times a week for support from the outpatient nursing team to administer the PEG feed. Again they outline the advantages and disadvantages of this proposal.*

***Proposal 5** – referral for weight restoration treatment under intensive care including general anaesthesia. They outlined the potential for new trauma during this treatment, as well as risks of general anaesthesia at this low BMI. They also outline the potential consequences of sudden weight gain.”*

9. Dr Cahill considered that CC lacked capacity to make decisions about her treatment concerning nutrition and her physical health. He emphasised that there are many “*different facets and overlaps*” to her condition. He observed that “*to discuss capacity in general terms is impossible given the many different aspects of the case, likely comorbid psychiatric comorbidities and different clinical decision to be made*”. A great deal of effort and energy has been expended on identifying labels. I have been told that in clinical practice, it is widely recognised that females with ASD and disordered eating often present in an atypical way. CC, all agree, presents atypically. She does not believe that she truly has anorexia, she believes her central problem to be depression.
10. The labels are, to some degree, a distraction. Dr Cahill considers that CC has the ability to outline the advantages and disadvantages of particular facets of her treatment, but is, ultimately, unable to use and weigh the information necessary to arrive at a decision. This is considered by Dr Cahill to be a consequence of her anorexic/ disordered eating/ ASD thinking. He considers that she is fixated on the “*numbers*” (relating to body mass index (BMI)) whether that be due to “*a drive to be thin*”, i.e. anorexia, a need for control; a combination of anorexia and ASD; a desire to die; an emotionally unstable personality disorder (EUPD)/ ASD/ depression. Ultimately, CC is, in Dr Cahill’s view, unable to make decisions about her nutrition. Dr Cahill was not convinced that CC’s nutritional restriction is a facet of suicidal behaviour. He thought it more likely to be an expression of “*not wanting to feel as she does any longer*” (my emphasis) and her inability to articulate it. In addition, her poor physical health impedes her real insight into the seriousness of her current situation, and the desperation of her body’s requirement for nutrition.
11. Though a consensus has emerged on the question of capacity, it is important to set out the legal framework upon which the Court must make its own conclusions in respect of capacity.

Legal Framework

12. It is important to preface my analysis of the law by stating the uncontroversial fact that there is no obligation on a patient with decision-making capacity to accept life-

saving treatment, and doctors are neither entitled nor obliged to give it. As set out by Lord Brandon in *Re: F (Mental Patient: Sterilisation)* [1990] 2 AC 1: “*a doctor cannot lawfully operate on adult patients of sound mind, or give them any other treatment involving the application of physical force ... without their consent’, and if he were to do so, he would commit the tort of trespass to the person.* [55]”

13. As Lord Goff thereafter observed in *Airedale NHS Trust v. Bland* [1993] AC 789 at [864]: “*... the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so.*”
14. The right to self-determination was expressed succinctly by Judge LJ (as he then was) in *St George's Healthcare NHS Trust v S* [1999] (Fam) 26: “*Even when his or her own life depends on receiving medical treatment, an adult of sound mind is entitled to refuse it.*”
15. As set out by Baker J (as he then was) in *An NHS Trust v A* [2013] EWHC 2442 (COP) at [30]: “*There is no doubt that this principle applies in the context of choosing whether to refuse food and drink (see, for example, Secretary of State for the Health Department v. Rob* [1995] 1 All ER 677 *and A Local Authority v. E and Others.* [2012] EWHC 1639). *Thus, if Dr. A. has the capacity to make decisions as to whether to take food and drink, he is entitled to starve himself to death if he so chooses. The question is: does he have the capacity?*”
16. Additionally, at para 47, Baker J observed: “*it is not uncommon for people to go on hunger strike in the hope that the Government will be forced to change its policy. Hunger strikes are a legitimate form of political protest. Not all hunger strikers are suffering from a mental disorder*”
17. In *London Borough of Tower Hamlets v PB* [2020] EWCOP 34, I recently reviewed the applicable law which can, conveniently, be reprised here. The MCA provides a specific statutory definition of mental capacity which is termed to be “decision

specific”, predicated on a “functional approach”, evaluated in the framework of a “diagnostic threshold”. Thus, at the core of the Act is a central distinction between the inability to make a decision and the making of a decision which, objectively, would be regarded by others as unwise. Fundamentally, the Act emphasises the right of the individual, in exercising his or her personal autonomy, to make bad decisions even extending to those with potentially catastrophic consequences (see ***Barnsley Hospital NHS Foundation Trust v MSP*** [2020] EWCOP 26).

18. The presumption of capacity, section 1(2), is the benchmark for decision makers in this sphere. The Act reinforces this by requiring that 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*”. As has been said on many occasions, the scope of these unambiguous provisions must be fully recognised and vigilantly guarded. The philosophy informing the legal framework illuminates the point that this case highlights, namely “*a person is not to be treated as unable to make a decision merely because he makes an unwise decision*”.

19. It is important to identify and define the issue in question, see ***PC v NC and City of York Council*** [2013] EWCA Civ 478 at [35]. There, the Court of Appeal stated that: “*The determination of capacity under MCA 2005, Part 1 is decision specific.... all decisions, whatever their nature, fall to be evaluated within the straightforward and clear structure of MCA 2005, ss 1 to 3 which requires the court to have regard to 'a matter' requiring 'a decision'. There is neither need nor justification for the plain words of the statute to be embellished.*”

20. It is necessary to set out Section 3 MCA, which 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.”

21. Paragraph 4.30 of the Code of Practice also requires to be considered: “Information about decisions the person has made based on a lack of understanding of risks or inability to weigh up the information can form part of a capacity assessment – particularly if someone repeatedly makes decisions that put them at risk or result in harm to them or someone else.”

22. It is also important to highlight that it is not necessary for a person to use or weigh every detail of the respective options available to them to demonstrate capacity, the salient factors are key: see *CC v KK and STCC* [2012] EWHC 2136 (COP) at [69]. Importantly, it must always be recognised that though a person may be unable to use or weigh some of the information objectively relevant to the decision in question, they may nonetheless be able to use or weigh other elements sufficiently well so as,

ultimately, to be able to make a capacitous decision, see **Re SB [2013] EWHC 1417 (COP)**. It is not necessary to have every piece of the jigsaw to see the overall picture.

23. Even where an individual fails to give appropriate weight to features of a decision that professionals might consider to be determinative, this will not in itself justify a conclusion that P lacks capacity.
24. Whilst the evidence of psychiatrists is likely strongly to influence the conclusion of the Court as to whether there is “an impairment of the mind” for the purposes of section 2(1) MCA, the ultimate decision as to capacity is a judgment for the court see (**Re SB [2013] EWHC 1417 (COP)**). In **PH v A Local Authority [2011] EWHC 1704 (COP)** Baker J observed at [16]: *“in assessing the question of capacity, the court must consider all the relevant evidence. Clearly, the opinion of an independently instructed expert will be likely to be of very considerable importance, but in many cases the evidence of other clinicians and professionals who have experience of treating and working with P will be just as important and in some cases more important. In assessing that evidence, the court must be aware of the difficulties which may arise as a result of the close professional relationship between the clinicians treating, and the key professionals working with, P”*
25. It is important that I emphasise that CC told me that she believes that she has capacity to understand her medical treatment. When by way of example she was confronted with her vacillation on the question of her attitude to dying, she told me she contradicted herself, but asserted, rightly, that did not mean she was incapacitous. *“We all contradict ourselves”*, she said. She was also able to summarise the full range and detail of her various conditions, in an impressive and eloquent manner. Despite what ultimately emerged as a consensus, amongst the psychiatrists, that CC lacked capacity, I have nonetheless given it a great deal of careful thought and consideration. Evaluating capacity in the context of eating disorders is a challenging process, which demands, to my mind, particular subtlety of thought. It is too easy to infer incapacity by focusing on the consequences for the patient of non-compliance with treatment. In this sphere, there is always, in my judgement, a pull towards paternalism. This requires to be resisted. The force is distinctly strong and stark when, as here, considering the risk to the life of such an obviously talented young person. The MCA

does not require me to determine capacity on the balance of probabilities, rather, it requires me to apply that test in evaluating whether the presumption of capacity has been displaced. This is the statutory bulwark protecting personal autonomy.

26. Ultimately however, I agree with Dr Cahill that there is a distinction to be made between insight into a decision, and an ability to weigh the information surrounding it. The former engenders the decision, the latter is ultimately formulation of the question. The impact on CC of her ASD has, despite her efforts, eluded her understanding, in the way that Dr Cahill describes (see emphasis in paragraph 10 above). It is an important and integral element of her eating disorder. It is this inability to weigh and balance the impact of her ASD into the decision surrounding her treatment, that has, ultimately, robbed her of capacity on the issue. It is intensely frustrating to her, and profoundly distressing, not least because in this context, this, otherwise, impressively articulate young woman cannot identify the correct words to articulate her feelings.

27. Dr Cahill met with CC for two and a half hours on 28th October 2024. He told me that he should have liked to have spent longer with her, but time did not permit. CC told him that there were, as she termed it, a number of issues, which looking back at them, she can now see she was struggling with. She identified primary school as the start of her difficulties. She is in no doubt as to her own intellectual abilities. She has, she told Dr Cahill, “*a clever brain*”, but she added, “*I liked to do things my own way, I didn’t like the rules in primary school. I was never particularly happy*”. Dr Cahill records the following in his report:

“4.3 She told me that high school was worse. ‘They came down too hard on me. I didn’t like the rules. They invented punishments. I’d get punished at school. Then my parents would grill me. I couldn’t communicate, it was torture. It was bad enough having trouble at school, then at home. I didn’t want to talk, it was just a blockage.’ She told me that she was never scared of the punishment, rules or possibility of being expelled. ‘I was dressing the part, doing the part with all the Judaism. I was wondering when it would all blow up. It had to.’ She told me that she was never able to concentrate in

school, 'because I was clever, everything was overlooked. I was bored. I never wrote notes. I couldn't concentrate for more than two seconds.'”

28. CC was able to identify the start of her eating disorder which she narrates as emanating from her ‘depression’:

“ 4.4 She described episodes of not eating in high school. She would stop eating for a few days. 'I got very overwhelmed, new places, new people.' She described a school weekend away in year 10. 'It took a long time to get there. I was on a high, very energetic, having fun, I was being mischievous, getting into trouble. Then I crashed, down and down, I stopped eating and drinking. I was low in mood, stayed in bed. They took me to hospital.' She then returned home and began eating again. She said the same thing happened at the end of Year 10 when in Camp America. A similar episode occurred in year 11 whilst at home. She denied that she felt any sense of power during these episodes, not as a way of eliciting care and nurturing. There was no sense of achievement. 'No, it was just something that was happening, from year 10 I was getting really depressed.'

4.5 She was sent to College ... at 16. 'There weren't many choices in my community. I didn't want to go, I didn't have a choice, but I didn't know what I wanted either.' She said that she stayed in bed for a lot of the time. Due to COVID, she was sent home, 'It was perfect, I never had to go back.'”

29. I find CC’s responses to Dr Cahill at the meeting on 28th October 2024 to provide a helpful insight into her functioning and her perception of her present situation. That is not to say that I take everything she says in that meeting at face value. I do not. My understanding of CC derives not solely from what she tells me, but what her parents, doctors and nurses say too. I consider it to be necessary to set out Dr Cahill’s report in some detail. Some of that report makes distressing reading:

“4.6 She had volunteered with children with special needs which she enjoyed. She began working in this role around 2020/2021. She recalled that in Summer of 2021 she was working on a camp and felt quite depressed. She recalled that her eating was still an issue, in that she was not eating adequately, but was clear it was not weight related. She described having ‘disordered eating.’ On further questioning, she told me that she was not eating enough, that she stayed in bed not eating, that she would start eating very late at night and would only have one meal a day. She denied that she was worried about weight at this stage. She said ‘I was very unhappy; it was my only way of expressing it. I guess some of it was about control. I was weighing myself often, but it was more about....not cause of how I looked.’

4.7 She explained that there was still ‘plenty of stuff I was being forced to do. I still didn’t even have a smartphone. I was told off for not praying, too short skirts. I was being controlled big-time.’

4.8 She took an overdose of painkillers during the week she was admitted to [Hospital] in October 2021. She did not tell anyone. She stopped speaking. When asked what drove this, she said ‘I shut down. I wanted to die. I stopped eating and drinking. I had nothing to say to them. I was angry. I felt misunderstood in general. I was never able to communicate.’

4.9 She told me that she was sectioned under the Mental Health Act (MHA) as she was mute and not making eye-contact. She was transferred to a psychiatric ward for five weeks. ‘I wasn’t eating and drinking, my brain wasn’t functioning. My BMs were dropping. They stuffed Glucogel in my mouth, held me down. I didn’t know what was happening. The other patients were scary. It was a traumatic time.’ She

talked about being held down to give fortisip and suffering with refeeding syndrome.

4.10 She was then transferred to [the Ward]. She described how she felt out of control. 'Change has always been hard for me. I didn't know what was happening. I was self-harming, cutting for a while, cutting badly.' She told me that she had been self-harming since she was young. When asked about the reasons for her self-harm, she said 'I don't know, I just did it, I liked it, the pain, the blood, I liked it all.'"

30. As is obvious from the above passages, CC is inclined towards striking and occasionally slightly dramatic use of language. I noticed that when she was speaking to me.

31. The following passages strike me as providing the foundation for Dr Cahill's ultimate conclusion:

"4.13 Initially, she refused to go to [Ward]. She told me she was kicking and screaming, crying and hysterical. She refused all treatment. 'They tubed me, they gave me glucagel.' She told me that she was seeing visitors and going out with friends. She was asking friends to bring her food and drink that she was craving. But on the ward, she would not eat. She was only nourished through NG feeding and oral supplements. When challenged why this was the case, she replied, 'If I make a decision, I get stuck, so if I don't want to eat, I won't eat. Its always the same, an inability to flex.' She talked about headbanging when she became overwhelmed. She was NG fed until the point where she was discharged. 'On the day I left, I was still restrained.'"

4.14 When I examined her cognitions around this time, she said 'I knew that they would give it to me anyway, either by supplement or NG. It wasn't a fear of fatness, or a drive to be

thin. I was obsessed with the numbers, it was a control of the numbers.' She added that towards the end, she 'couldn't care less about the weight.' She told me that she was eating with friends and was not worried about the weight. She described coming home from hospital and having a pizza party which she instigated. She said that throughout all this, in the background, she still felt a religious pressure, and gave some examples, like when she was at home, she would have to wear a skirt, but when with friends, she wore leggings.

4.15 She was readmitted again soon after discharge. 'I didn't know what was expected of me. I didn't have a discharge meal plan. I was self-harming badly. My eating was disordered. I stopped eating again.' She remembers that the 'straw that broke the camel's back' was when she gained weight in the community and weighed herself. She felt like she had 'lost control.' 'It's like I'm all or nothing. I was so unhappy in general. They pushed my weight up, but it didn't solve my depression.'

4.16 During the February to May 2022 admission, she described the situation getting a lot worse. 'The longer you spend on an [Eating Disorder] ward, the more you develop an ED.' She told me that she continued to struggle with communication, and therefore struggled to engage with therapy and groups. 'Nothing was offered therapeutically, I didn't like the one-to-one therapy, I still felt misunderstood.'"

32. When Dr Cahill asked CC why she had stopped drinking, she told him that she had always had a problem with fluids, *"I don't like the number going up. Doesn't matter if it's fluid, food. Don't care what's making the number go up. I just don't like seeing the number going up. That's why I'm weighed in underwear. I've never falsified my weight."* In response to Dr Cahill's question, she said of her clinical situation

“sometimes it makes me happy. Depends what side of the brain is thinking about it.”
Later she told Dr Cahill *“I don’t like feeling misunderstood, it triggers me”*.

33. Though I have quoted extensively from Dr Cahill’s account of his meeting with CC, it is important to set out her response to the treatment plan.

“4.29 ‘Give me treatment for my depression, then help me with my eating. I need to have a plan. I know I could die at any minute. My anxiety was so high, I was bound to kill myself somehow. I was not just going to agree to increase the feed, increase the feed, that’s not a plan out of this. That makes me feel hopeless.’

4.32 ‘I get so stuck. Even if I change my mind, I can’t change my mind.’”

34. What strikes me from all of this is not any disagreement between Dr Cahill and CC, but the convergence of what they are both saying, albeit in different terms. When CC says, as she does so frequently, that she *“can’t see the number go up”*, Dr Cahill perceives that as linked inextricably to her ASD. CC prefers to interpret this as *“her depression”*. When Dr Cahill emphasises her inability to articulate *“how she feels”* in the context of her ASD, it is notable that CC’s language breaks down and becomes contradictory and ambiguous *“... even if I change my mind, I can’t change my mind”*.

35. CC’s treating psychiatrist (Dr W) considers that CC has key symptoms of an eating disorder. He predicates this on the fact that CC restricts her intake, fixates on weight, and engages in compulsive binge/ purging *“to a life threatening level on a daily basis”*. He also notes that CC is fixated on eating *“and cannot stop once started”*. This latter point was very much confirmed by CC’s father in his evidence. When CC leaves the ward to go home, it is there that she binges (and purges). I asked F what CC would eat. My thoughts on this question were directed to try and gain some idea of her calorific intake, which Dr W had told me was higher than the 200 calories she received at hospital via the PEG, but otherwise it was difficult to be clear about. Her calorie intake is relevant to assess her resilience to treatment. I had not been expecting the answer. CC binges food on an almost industrial scale. Looking at her in the

courtroom, so plainly malnourished, I found it difficult to imagine how she could eat such vast quantities of food on a daily basis and remain as she is. It is also difficult for the lay person to understand why it is CC requires to be fed artificially and at length in hospital, when she can eat and drink at home. All this serves to illustrate the labyrinthine complexity of her condition.

36. CC recoils from Dr W's emphasis on anorexia for the reasons which have been recorded above. Dr W agrees that her eating disorder is atypical but considers her behaviours cannot be explained by her ASD or depression alone. The difference between Dr W's diagnosis and that of Dr Cahill is the latter's emphasis on the centrality of the ASD, and the priority that must be given to treating it. Dr W concludes that CC is at a life threateningly low BMI; she actively avoids restoring any weight; interferes with interventions aimed at achieving weight gain and underestimates the degree of her malnutrition and associated risks. He concludes:

"Given these factors, [CC] meets the diagnostic criteria for anorexia nervosa. To clarify, anorexia simply means lack of appetite with subsequent weight loss. Anorexia nervosa is a mental illness, as defined in ICD 11 and other diagnostic manuals."

37. CC's mother has obviously thought long and hard about her daughter's motivations surrounding her maladaptive relationship with food. Whilst she was receptive to everything Dr Cahill has said, she told me that she thought that on some level, and contrary to what CC says, her daughter enjoyed looking thin. More generally, CC is fastidious about her appearance and her clothes which are stylish and expensive. How she looks, therefore, is plainly important to her.

38. One treatment option which Dr W has advocated, enthusiastically, is Esketamine. This is a psychedelic drug and would require panel approval at the hospital. Dr W told me, in evidence, that he did not think there would be a problem in getting the approval of the panel. I was rather surprised at Dr W's confidence. Esketamine, as a treatment for resistant anorexia nervosa, has very little evidence base. There have

been no trials in this country and, inevitably, no peer review. Dr W has had only one patient who he has treated in this way. The treatment, he tells me, was successful. He has discussed Esketamine treatment with CC. She is immensely enthusiastic about it. Indeed, it has become the repository of all her hopes. She is so intensely invested in it, that a decision not to go forward is one she finds extremely difficult to contemplate. Dr W is acutely aware of all of this.

39. In his oral evidence, Dr W made a strong case for CC, in her quest to be treated with Esketamine. He was plainly concerned as to how CC might react if this treatment plan was not confirmed as being in CC's best interests. Dr W is very committed to his patient's care and anxious about her prognosis. I should also state that CC has been in the courtroom for most of the hearing. She has listened attentively.

40. I note that in his report, Dr W's language was rather more measured than in the witness box. He emphasised that CC would have to be physically well enough to tolerate Esketamine. The importance of this is obvious given Dr W's own description of CC's behaviour as "*life threatening on a daily basis*". He signalled that CC's blood pressure and ECG would need to be at, or close to her baseline, with stable electrolytes. That is difficult to achieve when she purges. Accordingly, it would be necessary for CC to be treated on the ward. She has been resistant to this historically, and being on the ward causes her significant distress. Esketamine has a "*profound psychotropic effect in the short term*", as Dr W termed it in his report. It also requires vital signs monitoring when being administered. Selective Serotonin Reuptake Inhibitors (SSRIs) require co-prescription with Esketamine, used as an antidepressant. CC has agreed to this but, I note she has a long-standing history "*with lack of response to multiple antidepressants of different classes at adequate dose for an adequate period of time*". Dr Cahill recorded the history of antidepressant prescription in his report, which included the following: Fluoxetine, Sertraline, Mirtazapine, Venlafaxine, Duloxetine, Vortioxetine, Pregabalin, Quetiapine, Aripiprazole, Olanzapine, Naltrexone, Clonazepam and Promethazine.

41. In his report, Dr W described Esketamine as having "*few absolute contraindications*". He considered that it "*could be an option for treatment resistant depression*" (my emphasis). He described it as having "*novel mechanism of action*"

compared to typical antidepressants”, recording that it has *“limited emerging evidence for treatment of resistant anorexia”*. He concluded that treatment could be “tried” on an inpatient basis with a *“potential to **possibly** be prescribed on an outpatient basis”* (my emphasis). For completeness, I note that Dr W’s report also contained the following paragraph:

“[CC] is keen to try lithium, given its evidence in mood disorders and treatment resistant depression. However, her history of poor medication compliance, frequent vomiting and fluid restriction, with associated kidney injury as well a low BMI, make this option unsafe. If prescribed it would likely cause life limiting renal failure and / or acute toxicity which could lead to brain damage as well as cardiac arrhythmia, with high risk of a fatal outcome in the short and long term.”

42. In his oral evidence, Dr W said that he considered that he had a good working relationship with CC, and that she got on well with the eating disorder nursing team. He told me that Esketamine is a licensed drug which can be used in a psychiatric emergency. Its primary use is in anaesthetics, in which context, it has been used regularly for over 20 years. Dr W described it as *“a safe drug”*. In the context of anaesthesia, I do not doubt that is an accurate description, but I consider it to be a bold claim, on the available evidence, for its limited use in treatment of resistant anorexia. Dr W said that he thought that its impact on CC might be to make her *“giggly”* and lightly *“intoxicated”*. This, I took to be based on the response of his previous patient. Dr W amplified the range of likely responses. Esketamine, he told me, has a *“dissociative effect”* on patients, i.e. it alters consciousness. It can create a *“lightness of the body”*, a sense of *“floating”*. He also described what he termed *“an enhanced feeling of being in the room”*. The drug *“heightens the senses”*, *“material may be felt more keenly against the skin”*, *“smells will be experienced more strongly”*. Esketamine is a psychedelic drug and, as such, causes *“visual distortions, hallucinations, and fragmented consciousness”*. Side effects may include psychological issues, a risk of future substance misuse (described by Dr W as theoretical), raised blood pressure, arrhythmia (thought to be a *“remote”* risk).

43. Whilst the hallucinations might be benign or even pleasant, it is also possible that they might be distressing and cause agitation. Both would require careful management and supervision. As Dr W reminded me, CC already has 1:1 supervision. Nonetheless, a pleasant hallucination might, he suggested, cause CC to want to go outside and she would have to be restrained to prevent her from doing so. An unpleasant experience would require her to be talked down by soothing words or, if necessary, by medication (benzodiazepine).
44. Alarming though all this sounds, it is not difficult to see why it might be worth trialling if the alternative is speedy deterioration and death. Neither would it be right to clothe this balance in ambiguous language. It requires to be confronted, as CC and her family have done.
45. In his review of CC's antidepressant medications, Dr Cahill considered that none of them had worked because there had not been sufficient focus on the impact of ASD (for all the reasons discussed above). In his evidence, he told me that nothing was likely to work unless the ASD was brought into sharper focus and with the assistance of an Occupational Therapist. He noted that there was no Occupational Therapist in place, and identified that as a key role, including in coordinating support. The Trust has immediately recognised this and has ensured that an Occupational Therapist will soon be appointed and able to identify reasonable adjustments for CC to maximise therapeutic potential. I regard this as a key piece of evidence. Although we are dealing with a very different type of drug in Esketamine, if Dr Cahill is correct, it still runs a risk of failing, if the impact of ASD is not addressed in advance. That outcome has the potential to be catastrophic for CC. To invest so much hope in Esketamine, only for it to fail, would leave CC with no hope and no alternative plan that she could begin to contemplate. If Esketamine is to be tried, it must have the best possible opportunity to be successful. That is not the situation here. At the moment, there is a real risk that to move forward to such a treatment regime might be setting her up to fail.
46. Ms Paterson KC, acting on behalf of the Official Solicitor, has been able to identify a properly convened medical trial of the use of Esketamine in resistant anorexia that is due to commence in London quite soon. I understand that approaches will be made to see if CC may be included within the trial. Dr Cahill considered that the Esketamine

treatment was not, at this point, in CC's best interests. I agree. I also regard that conclusion as inevitable in the light of his reasoning.

47. It is important however, that I signal to CC, in very clear terms, that she must not perceive my decision as ideologically resistant to what may yet prove to be, and I hope will be, a progression in the treatment of this awful and insidious condition. Esketamine may well be an option for CC, perhaps even in the near future, but if it becomes an option, it must have the best possible chance to succeed, following the plan which Dr Cahill has suggested, and which I am persuaded is in CC's best interests. That plan is to be refined and considered further at a directions hearing in a few weeks.

48. I delivered an ex-tempore judgment at the conclusion of these proceedings. A note was taken and I have perfected and amended it. I know that CC will read this very carefully. As I perfected the judgment, I was conscious of the likely scrutiny that she will give it and have tried to express myself in terms which are both honest and sympathetic to her circumstances. My respect for her and her family is, I hope, obvious. It is also important that I emphasise that she is surrounded by committed doctors and nurses. Nurse A gave evidence before me by video link at short notice and on CC's request. He had been on the screen for barely a matter of minutes before it became entirely obvious to me why CC had such confidence in, and affection for, him. He is plainly a crucial part of CC's support. His understanding of CC and his commitment to her care was extremely impressive. CC personally, and the system more generally, is lucky to have him. I indicated, at the conclusion of the evidence, that I wanted him to see the judgment in order that he could fully understand my decision and discuss it with CC if she wishes to do so. Mr Fullwood, on behalf of the Trust, has assured me that will be done. Whilst it is not the judgment CC would have wished for, she will, I am confident, understand it, even though she will not agree with it. I hope she will be able to take some heart from it.

49. Finally, the consensus has been that CC lacks the capacity to litigate. The challenges she faces in weighing and balancing the complex facets of her competing medical needs also, inevitably, reverberate on her ability to conduct proceedings in which

those needs are central. Here, though it is not always the case, the two are inextricably linked. CC has been proactively involved in the conduct of these proceedings. She has also had the benefit of Leading Counsel and the Official Solicitor acting on her behalf. I have watched her give regular instructions to her team. At her request, she has spoken to me in the presence of the Official Solicitor's representative on two occasions. Her voice has been heard loudly and clearly.