Mental capacity and medical treatment—anorexia nervosa and forced feeding (An NHS Foundation Trust v AB)

26/08/2020

Private Client analysis: The issue in this case was whether, as the trust asserted, AB lacked capacity to make decisions about treatment relating to anorexia nervosa. She had suffered from this condition since the age of 13 and was now 28. All treatment, including nasogastric tube feeding which was the only life-prolonging treatment now on offer, had failed, and her weight of just under 26 kg (a body mass index of 9.7) was incompatible with life. Tube feeding now would cause her enormous trauma, put her at significant physical risk and could itself be fatal. The court found that AB's anorexia was so chronic and severe that any decision she made about food, calories or weight gain could not be considered capacitous. The court also agreed that it was not in AB's best interests to undergo further tube feeding, with or without restraint. AB died on 23 August 2020, before her application for permission to appeal the capacity decision was listed. Written by Katie Gollop QC, barrister at Serjeants' Inn Chambers, instructed in this case by Laura Hobey-Hamsher of Bindmans LLP.

An NHS Foundation Trust v AB [2020] EWCOP 40

What are the practical implications of this case?

Similar facts have been before the High Court five times since 2012. On each occasion, the court has determined that the person lacked litigation capacity and the capacity to make a decision about their nutrition. AB was unique in that the trust accepted (and the court did not disagree) that she retained capacity to litigate the proceedings. If ever there was a case where the question, 'Can a person suffering from severe, enduring, treatment-resistant anorexia have capacity to make a decision about treatment to produce weight gain?' might have been answered in the affirmative, this was it. And yet the answer was the same.

The seeming inevitability of the outcome has significance for how this situation should be approached in future. The making of both a valid advance decision and a valid lasting power of attorney (LPA) requires that the individual has capacity and is over 18. If the condition is severe and starts early, it may be that capacity will already be lacking by that age. But to give them the best chance of having their wishes and decisions effected, patients should be advised about these options.

Where the treating team believes that further treatment would be futile, traumatic, risky, inimical to the patient's best interests and contrary to their strongly held wishes, trusts should think hard about whether it is necessary to seek declaratory relief.

If it is, proceedings should be issued without delay. And trusts should not assume that just because the patient has anorexia, they will lack capacity to litigate proceedings about treatment for their anorexia.

What was the background?

AB had been engaged with psychiatric services for her eating disorder since the age of 13. She had had 11 periods of in-patient treatment, some under the Mental Health Act 1983. She had been tube

fed using restraint and gave a graphic account of the horrors that had involved. Treatment provided no lasting benefit because she could not maintain the weight after discharge.

Tube feeding would require at least six months in hospital. If removed, as it would be, the tube would have to be re-introduced twice a day using restraint. Since AB had osteoporosis, she was at risk of bruising and broken bones. There was a risk of re-feeding syndrome causing tissue swelling, hepatitis and liver failure, as well as cardiac arrest and sudden death. Damage to her mental health was certain.

AB was desperate to avoid that treatment, the prospect of which caused her panic attacks. Her every wish was to stay at home with her beloved parents and pets and enjoy her life with them there. A best interests hearing in July 2020 concluded unanimously that further tube feeding would fail and not be in her best interests.

The trust accepted that AB had capacity to make decisions in all aspects of her life, including medical treatment that did not involve nutrition. It also accepted that she had the capacity to understand and retain information relevant to such decisions and was well able to communicate her decision. And it accepted that she understood the risks of tube feeding and the fact that if she was not tube fed, she would die of malnutrition. But it asserted that AB had the 'overvalued ideas that are typical of this disorder' (the 'desire to be thin and avoidance of being fat') and that undue weighting of these made her unable to make a decision.

What did the court decide?

The court was concerned with section 3(c) of the Mental Capacity Act 2005 (MCA 2005) headed 'inability to make decisions'. This states that a person is unable to make a decision for themselves if they lack any one of four abilities, the third being the ability to 'use or weigh [information relevant to the decision] as part of the process of making the decision'.

In *PCT v P, AH and The Local Authority* [2011] 1 FLR 287, the 'use and weigh' domain was described as 'the capacity actually to engage in the decision making process itself and to be able to see the various parts of the argument and to relate one to another'.

It may be thought that AB did this. And she was better placed to do so than her predecessors. No personality disorder, body dysmorphia, dependency on painkilling drugs or alcohol or other condition affecting her ability to analyse the arguments was present. Unlike some of those before her, she acknowledged the severity of her anorexia and was clear-eyed about the certainty of death if she did not accept tube feeding to put on weight. As the judge found, 'she had very sound and straightforward reasons' for not wishing to repeat the trauma and pain of further hospital admissions which were 'based solidly' on her lived experience. And exceptionally, she retained capacity to litigate. In *Sheffield City Council v E* [2004] EWHC 2808 (Fam), Judge Munby said that 'only in unusual circumstances will it be possible to conclude that someone who lacks subject-matter capacity can nonetheless have litigation capacity'.

Why then was she held unable to make a decision about whether or not to have more tube feeding?

The judge distinguished AB's reasons from her 'ability to respond rationally' to advice she was being given to gain weight to survive. That ability was, said the judge, 'critically impaired by an intense and irrational fear of weight gain' and the fact that AB did not want to die was 'the clearest manifestation of the extent to which her judgment was impaired'. Despite the fact that the desire to be thin formed no part of AB's reasons for her decision not to undergo tube feeding, the court

agreed with the trust that her 'fixated need to avoid weight gain at all costs' meant that 'true logical reasoning in relation to these specific matters is beyond her capacity or ability'. This condition-centred approach led the judge to the finding (wider than was required given that the specific decision related to tube feeding alone) that AB lacked capacity to make 'any decision' about food calories or weight gain.

MCA 2005, s 2(3)(b) says that a lack of capacity cannot be established merely by reference to a person's condition 'which might lead others to make unjustified assumptions about his capacity'. In *A Local Authority v E* [2012] EWHC 1639 (COP) the expert in the case (who gave evidence in each of the five anorexia cases preceding AB's) stated his view that 'anyone with severe anorexia would lack capacity to make such a decision'. Without reaching a conclusion, Mr Justice Peter Jackson was alive to consequences of accepting that opinion: 'I acknowledge that a person with severe anorexia may be in a Catch 22 situation regarding capacity: namely that by deciding not to eat, she proves that she lacks capacity to decide at all'.

It is to be hoped that at some point, the Catch 22, and any legal route out of it, will be considered by the Court of Appeal.

Had she not died before her appeal was listed, AB would have argued for a decision-centred, not condition-centred, approach. That would allow for an intense focus on the individual's approach to the specific decision before her (not whether as a result of having anorexia she lacked capacity to make any decision about food), the time at which the decision falls to be made (here, right at the end of life), and a search for any evidence of impaired thinking in terms of statements or reactions from the patient, over and above the existence of severe, enduring anorexia (here absent). In *SB (a patient; capacity to consent to termination), Re* [2013] EWHC 1417 (COP), the openness of the judicial mind to the fact that a person's impairment of the mind (bipolar disorder with paranoia) may affect some but not all of their reasons and reasoning, allowed for a different decision on capacity.

In the meantime, trusts treating patients suffering from anorexia should advise them about the possibility of making an advance decision or LPA as soon as they reach 18. For those who do not, or may not (by reason of incapacity), trusts should consider whether it is necessary to approach the court at all, following the Supreme Court's decision in *An NHS Trust and others v Y* [2018] UKSC 46. Where there is no dispute about best interests, it may be kinder and less injurious to the patient's autonomy, particularly at the end of life, not to have them declared incapable of making their own decision.

Case details:

- Court: Court of Protection
- Judge: Mrs Justice Roberts
- Date of judgment: 16 August 2020

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