Limiting Autonomy? Mental Capacity to Refuse Treatment in the UK

Case Note: Re E (Medical treatment: Anorexia)(Rev 1) [2012] EWHC 1639 (COP)

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On 15 June 2012, the full judgment of the Court of Protection of England and Wales in the case of *Re E (Medical Treatment: Anorexia)*[2] was published. The case was the result of an urgent application made by a local authority requesting guidance as to whether it should take steps to force-feed, against her wishes, a 32-year-old woman, E, who was suffering from extremely severe anorexia nervosa and was on the verge of death. The Court granted an order permitting the force-feeding, finding that E did not have capacity to make a decision about life-sustaining treatment and that feeding E against her will was in her best interests.

The case highlights the challenges faced when an attempt to respect the freedom and autonomy of an individual (howsoever disabled or otherwise) to make their own choices appears to come into conflict with the perceived need to preserve the life of a vulnerable person, in their "best interests". It appears to indicate that, when faced with this dilemma, the court is inclined to come down on the side of preserving life. This note summarises the case, focusing in particular on its discussion of E's capacity, before considering the right to equal enjoyment of legal capacity of persons with disabilities, as prescribed by the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD).[3]

Background to the Case

E's eating disorder began in her early teens following years of serious sexual abuse. Over the years prior to the case she had, at various times, been institutionalised for treatment. In addition to her severe anorexia nervosa (acknowledged to be a pervasive psychiatric illness), E had been diagnosed with alcoholism and an unstable personality disorder. At the time of the hearing, E had not taken solid food for a year, was refusing to eat and was only taking a small amount of water.

E had, for a number of years, consistently expressed the wish that she not be given life-sustaining treatment. She was described as "intelligent and articulate" and "fully aware of her situation"[4] and simply desirous of being "allowed to act as she wants".[5] In July 2011, E signed an "advance decision" in which she stated that she did not want to be resuscitated or given any medical intervention to prolong her life. In October 2011, she signed another such decision having gone so far as to willingly raise her body weight in order to seek to ensure that she be deemed to have the capacity to make the decision valid. No formal assessment of her capacity to make either decision was carried out contemporaneously.

By April 2012, after 18 years of unsuccessful treatments, E had been placed on a palliative care regime whose purpose was to allow her to die in comfort. It was only after five weeks of such care that the local authority decided to seek the Court's view on whether it should go against her wishes and force-feed her. The proposed treatment – which included admitting E into intensive care and force-feeding for a year or more (until her weight stabilised) before offering her therapies for her eating disorder and other problems – was acknowledged by the Court to amount to "a wholesale overwhelming of [E's] autonomy for a long period whose exact period could only be measured in hindsight once it was known whether the treatment had succeeded or failed".[6] Expert medical opinion before the Court as to the treatment's prospects for success varied but overall, the view at the hearing was that E's prognosis for recovery if the course of treatment was carried out was poor.[7]

Law Applied by the Court

Under the Mental Capacity Act 2005 (MCA) a person is presumed to have the capacity to make a decision in relation to their treatment unless it is established otherwise.[8] A person lacks such capacity if "at the material time he is unable to make a decision for himself because of an impairment of, or disturbance in the functioning of, the mind or brain".[9] Making a decision requires a person, amongst other things, to understand the relevant information and weigh that information when making the decision.[10]

The MCA also enables a person, in anticipation of any future incapacitation, to make an "advance decision" to refuse treatment if they have capacity to do so at the time of making the decision.[11] However, in the absence of a valid "advance decision," if a person lacks capacity a court may authorise action to be taken for them if that action is in their best interests.[12]

Under the Human Rights Act 1998 (HRA), in giving effect to the MCA, the court must, where possible, do so in a way which is compatible with the European Convention on the Protection of Human Rights and Fundamental Freedoms 1950 (ECHR). This includes respecting E's right to life (Article 2), not torturing E or subjecting her to inhuman or degrading treatment (Article 3) and respecting her private life (Article 8).

Issues

On the basis of its above legal analysis, the Court sought to establish:

(a) Whether E had, at the moment of the hearing, the mental capacity to make decisions about her treatment;
(b) If not, whether she had mental capacity when she had made either of her advance decisions, and whether either decision was valid and applicable; and
(c) If she lacked capacity and her advance decisions were not valid, whether it was in her best interests to receive life-sustaining treatment in the form of force-feeding.

In making its decision the Court relied on the opinions of a number of medical experts, including some who had worked with and treated E over the years as well as a court appointed expert who had not. The Court also listened to the views of E's parents. All parties involved acknowledged that it was a difficult case and stated that they would support the implementation of the decision of the Court either way. On the question of legal capacity, the views of the medical experts were mixed, with some (notably those who had worked

with and treated E previously) considering that she had at least had capacity when she made her advance decision and others disagreeing. On the question of E's best interests, E's parents had serious misgivings about the potential outcome of further treatment and, on balance, were of the view that it was in their daughter's interests for her wish not to be treated to be respected.

Decision

Before ruling on the issues, the Court stated that the case should have been brought before it much earlier and noted that those involved were aware of the ethical concerns raised by the case as early as 2009. However, the Court did not discuss and it does not appear that the issue was raised as to whether this delay had constituted a violation of E's rights under Articles 3 and/or 8 of the ECHR.

On the matter of E's mental capacity at the time of the hearing, the Court noted her condition as anorexic and held that her obsessive fear of weight gain meant she was unable to weigh the advantages and disadvantages of eating in any meaningful way. Secondarily it held that she was also currently sedated. For these reasons, the Court held that she did not have capacity to make a decision to refuse treatment which involved being fed. The Court acknowledged E's parents' comment that:

> "It seems strange to us that the only people who don't seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around any issues connected to food. There is a logic in this but not from the perspective of the sufferer who is not extended the same rights as any other person."[13]

The Court admitted that a person with severe anorexia was in a "Catch 22" situation "namely, that by deciding not to eat, she proves that she lacks capacity to decide at all".[14] However, it did not consider, nor was it apparently asked to consider, whether this raised any concerns as to discrimination against people with anorexia in relation to their right to respect for private life.

In relation to E's mental capacity at the time of her "advance decisions," rather than applying a presumption in favour of capacity, the Court held that the decision would only be valid and applicable if there was "clear evidence establishing on the balance of probability that the maker had capacity at the relevant time".[15] It held that this threshold was not met in the case and stated that in case such as E's, it would want to see a "full, reasoned and contemporaneous assessment evidencing mental capacity".[16] Although not expressly acknowledged by the Court, the effect of this decision is that a person who makes an "advance decision" when they in fact have capacity, may well have their wishes overruled by a court at a later date if, through no fault of that person's own, the state negates to carry out a full, contemporaneous assessment of their capacity at the time so their capacity may be proved in the future. Furthermore, the Court did not expressly consider the impact of section 1(3) of the MCA, which states 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".

On the question of what was in E's best interests, the Court held that "at its simplest, the balance to be struck places the value of E's life in one scale and the value of her personal independence in the other, with these transcendent factors being weighed in the light of the reality of her actual situation".[17] In

weighing this balance, the Court stated that "all human life is of value"[18] and that there is a "presumption in favour of the preservation of life".[19] Despite the court's recognition that "intelligent and articulate" E's "views are entitled to respect" and its acknowledgment that arguments in favour of trying all new treatment options, if taken too far, run the risk of discriminating against the incapacitated,[20] the Court held that "the balance tips slowly but unmistakably in the direction of life-preserving treatment".[21]

CRPD: Legal Capacity of Persons with Disabilities

As Mute explains, "legal capacity is fundamental to human 'personhood' and freedom".[22] Accordingly, it is particularly imperative that legal capacity is assured without discrimination on any grounds, including disability. The matter of legal capacity is not dealt with expressly in the human rights convention referred to by the court, the ECHR. However, Article 12 of the CRPD clearly emphasises the primacy of the need to respect the legal capacity of disabled persons. In reaffirming the right of disabled persons to equal recognition as persons before the law, Article 12 provides that:

> "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life…[and]…States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."[23]

It goes on to require that safeguards are in place to ensure that any measures relating to the exercise of legal capacity "respect the rights, will and preferences of the person" and are "proportional to the degree to which such measures affect the person's rights and interests".[24]

These elements of Article 12 of the CRPD give reason to think again about a number of aspects of the *Re E* judgment. Firstly, can it be anything other than a breach of a person's right to legal capacity on an equal basis for her to be incapable of making a "capacitous" decision as to the prolonging of her life, regardless of how articulate and considered she has been, on the basis that she has a disability? Perhaps the Court's acknowledgement of E's parents' point that only a person with severe anorexia is always deprived of legal capacity in relation to an "advance decision" of this kind is a sign that the current system falls short of Article 12(2) CRPD. Secondly, does the current system provide adequate support to such a person to help enable her to make a "capacitous" decision as required by Article 12(3) CRPD? There appears to have been a distinct lack of involvement by the local authority at the times when E sought to make her "advance decisions". Finally, although the Court did not agree, there are certainly strong arguments to be made that the prolonged force- feeding of an intelligent woman against her will amounts to a violation of her dignity and constitutes inhuman and degrading treatment. With such a serious violation of a person's rights at the very least a real risk, the need for strong safeguards is clear. Perhaps the case indicates the need for the UK to take a considered view of the current process for making determinations as to capacity to refuse treatment, in light of Article 12(4) CRPD.

In summary, whilst cases such as that of E are inherently extremely difficult for any court to decide, and whilst the ECHR does not deal with the issue of capacity rights expressly,

Article 12 of the CRPD provides useful guidance as to the approach to be taken. Courts should use this guidance in future, when dealing with such challenging cases.

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2 [2012] EWHC 1639(COP).

3 Despite its ratification by the UK in 2009, the CRPD was not discussed in *Re E (Medical Treatment: Anorexia)*. E's severe anorexia nervosa alone makes her a person with a disability under Article 1 CRPD.

4 See above, note 2, Paras 5 and 132.

5 Ibid., Para 76.

6 Ibid., Para 117.

7 The estimated prospects of success were placed between 10% and 30%.

8 S1(2) MCA.

9 S2(1) MCA.

10 S3(1) MCA.

11 S24 MCA.

12 S1(5) MCA.

13 See above, note 2, Para 52.

14 Ibid., Para 53.

15 Ibid., Para 55.

16 Ibid., Para 65.

17 Ibid., Para 118.

18 Ibid., Para 119.

19 Ibid., Para 140.

20 Ibid., Para 132 and 134.

21 Ibid., Para 140.

22 Mute, L.M., "Moving from the Norm to Practice: Towards Ensuring Legal Capacity for Persons with Disabilities in Kenya", *The Equal Rights Review,* Vol. 9, 2012.

23 Convention on the Rights of Persons with Disabilities, G.A. Res. A/RES/61/106, (2006), Article 12(2) and (3).

24 Ibid., Article 12(5).