Hard choices

Zahra Kanani looks at the lessons to be learned from NHS Foundation Trust v Mrs X *[2014], which marks a shift in the court's attitude to 'the right to life'*

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The issues that were before the Court of Protection in the case of *A NHS Foundation Trust v Ms X* [2014] illustrate the difficulties involved in applying legal principles to issues involving care and life-sustaining treatment. Cobb J's sensitive, empathetic and humane judgment is a sign that the courts are beginning to resist the application of Article 2 of the European Convention on Human Rights (ECHR) (the right to life) and the obligation to preserve life at all costs and moving towards respecting the autonomy of the individuals concerned.

Facts

Ms X was a young woman who lived alone in a private-rented bed-sit and had suffered from an enduring and severe form of anorexia nervosa for the last 14 years. Ms X also suffered from alcohol dependence syndrome which had caused chronic and now 'end-stage' and irreversible liver disease, cirrhosis following many years of alcohol abuse. For many years, Ms X had been trapped in an extremely destructive cycle of treatment and recurrent illness; she had repeatedly required specialist in-patient admissions where she had been force-fed in an attempt to arrest and reverse her anorexia. These admissions had only brought about short-term relief given that when discharged, she invariably sought refuge in alcohol which she used to alleviate her distress. Ms X had had over 45 admissions to hospital, sometimes for many weeks or even months at a time and had also received treatment at some of the most specialised eating disorder units in the country. When free to exercise her own choice, Ms X consciously acted to undo the weight gains achieved in hospital, to the point that her weight fell to a critical level and re-admission to hospital for re-feeding treatment once again became necessary. The judge acknowledged that the causes of Ms X's distress are 'multi-factorial' but included the treatment for her anorexia itself and the removal of her personal autonomy when she was treated.

At the date of the application, Ms X was in extremely poor health and malnourished with a body mass index (BMI) assessed to be in the region of 12.3-12.6 kg/m2. Her alcohol consumption was in the region of half a bottle (375ml) of vodka per day, or more. Her weight and BMI at the date of the application would have prompted a further admission to hospital but the doctors who had treated her in the past were of the view that further admission for compulsory feeding was 'clinically inappropriate, counter-productive and increasingly unethical'. Their experience revealed that on each recent admission, she had been more and more unwell (as a result of her anxiety to lose the weight gained in hospital during the previous visit combined with renewed alcohol abuse) and they predicted that she would now be more poorly and increasingly fragile than on previous admissions. In fact, Ms X had been on an 'end-of-life pathway' twice in recent months and it was said that 'her physical condition is now so fragile that her life is in imminent danger'.

Psychotherapy and talking therapies which could be facilitated in an attempt to investigate her underlying anorexia had been shown over many years not to work for Ms X. Consequently, the medical professionals involved were of the view that not only would in-patient

treatment once again involve painful, invasive and wholly unwelcome procedures for Ms X, it would be pointless in achieving any long-term benefits and would likely only serve to increase her alcohol consumption on discharge and accelerate her demise.

Application to the Court of Protection

For these reasons, the NHS Trust applied to the Court of Protection in August 2014 for declarations that:

- it was not in Ms X's best interests to be subject to further compulsory detention and treatment of her anorexia, whether under the Mental Health Act 1983 or otherwise, notwithstanding that such treatment would prolong her life; and
- it would be in her best interests, and therefore lawful, for her treating clinicians not to provide Ms X with nutrition and hydration against her will.

These declarations were sought by the NHS Trust in the context of the Trust's contention that Ms X lacked capacity to make a decision as to whether it would be in her best interests to receive treatment for her anorexia. As Cobb J pointed out, the doctors were not asking for authorisation to withhold treatment; treatment remained on offer for Ms X should she wish to avail herself of it. This was therefore, a case about the lawfulness of not compelling treatment.

Ms X herself supported the application and had made known her views to the court. Her litigation friend, the Official Solicitor, who, having heard and tested the evidence, did not oppose the application.

Cobb J acknowledged that the absence of any real opposition to the application did not relieve him of the onerous obligation to satisfy himself that he could and should exercise his jurisdiction in relation to Ms X and to make orders that protected and advanced her best interests. The court received oral and written evidence from three medical experts, two of whom had treated Ms X for several years, and a lay individual known as Ms Y who was said to be the 'best friend' of Ms X.

Medical evidence

Expert medical evidence suggested that, while nutrition was important to address the starvation of an individual who suffers from anorexia (thereby ensuring physical and medical stability), the only effective long-term treatment was psychotherapy; Ms X had in the past, repeatedly proved unable or unwilling to engage in such treatment and continued to express the view that she 'will not engage in "talking treatment"'. The experts opined that psychotherapy would only be effective if Ms X made an 'urgent, firm and enduring commitment to it'. They were of the view that periods of medical rescue (such as in-patient treatment and re-feeding) did not address the underlying causes of her anorexia, although such treatments had kept Ms X alive and less medically at risk, and so provided a window of opportunity for her to engage in therapy.

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Capacity

In determining Ms X's capacity to participate in the litigation and make decisions in relation to the subject matter in point (ie the treatment decisions in relation to her anorexia), Cobb J looked at the established principles set out in s1 of the Mental Capacity Act 2005 (the MCA 2005). He approached the issue from the starting point that Ms X must be assumed to have capacity unless it was established that she lacked capacity.

The court heard medical evidence from Dr A, who had been Ms X's clinician for the last five years. She was of the view that Ms X was able to understand and retain the information provided. However, due to ongoing severe body dysmorphia, false beliefs about her weight, shape and nutritional state, and her fear of weight gain, she was unable to apply that information to herself or believe in the need for it. In Dr A's view, Ms X did not appreciate the reality and importance of the associated risks of her condition, including death. She therefore concluded that while Ms X was able to understand the information around treatment and risks, she was unable to make decisions regarding her nutrition and the treatment of her eating disorder. The second expert, Dr Glover, went further and doubted Ms X's ability to understand all of the salient information relevant to the decision and was firmly of the view that Ms X was unable to weigh the relevant information.

On the basis of the evidence provided, Cobb J concluded that Ms X lacked the capacity to litigate and to make decisions about her eating disorder.

However, both medical experts were clear in drawing a distinction between Ms X's capacity to make decisions surrounding her eating disorder and her use of alcohol. They both considered that Ms X was able 'to understand, retain and crucially weigh up the decision around her drinking' which they felt was responsive; she appeared to be making choices about when to drink, when to drink more and when to drink less. Dr Glover again went further and was of the view that Ms X was able to weigh information such as the calorific content of alcohol and appeared to be aware of the consequences for her liver if she continued abusive drinking.

Cobb J accepted this position and noted that his jurisdiction was therefore limited to making decisions in Ms X's best interests only in relation to the treatment of her anorexia and not in relation to the management or treatment of her alcohol dependence disorder.

Advance decision

It emerged that Ms X had made an advance decision on 18 June 2014 in relation to future treatment of her liver condition. In that document, she had specifically set out the treatment that she did not wish to receive. The advance decision had been made in accordance with s24 MCA 2005. Cobb J was satisfied on the evidence that Ms X

had mental capacity to make it and as such, the advance decision was entitled to the 'fullest respect' and cited Lord Goff in the case of *Airedale NHS Trust v Bland* [1993]:

> ... 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.

The complication that arose was that, whereas Ms X had capacity with regard to her liver disease, she did not in relation to her eating disorder and any medical condition that warranted treatment might be as a result of the two conditions inextricably linked. Dr A observed that it would be 'extremely difficult' to establish whether any particular symptom was linked to her liver disease or to her eating disorder and that this could potentially lead to an 'inadvertent contravention of her capacitous wishes around the treatment of her liver disease'.

Cobb J was satisfied on the evidence that Ms X had mental capacity to make it and as such the advance decision was entitled to the 'fullest respect'.

Best interests

Cobb J then went on to consider Ms X's best interests. The best interest 'checklist' is set out in s4 MCA 2005. He noted at para 36 that he was 'naturally steered to exercise my judgement in this case in a manner which attaches the highest (even if not absolute) priority to the preservation and sanctity of life' and that this approach corresponded with Article 2 ECHR. He further mentioned that he was conscious of the importance of protecting Ms X's valuable and valued right to life in so far as he was able to do so.

The judge referred specifically to s4(5) MCA 2005 which provides that:

> ... where the determination relates to life-sustaining treatment he [ie the decision-maker] must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

In considering this provision, the judge had particular regard to paras 5.29 to 5.36 of the Code of Practice to the MCA 2005, notably para 5.31 which provides as follows:

> All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment.

The guidance contained in the Code of Practice reiterates that before deciding whether or not to withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available and consider all the factors set out in the best interests checklist, but especially any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.

In arguments advanced before the judge in this case, in considering Ms X's best interests, was the contention that the judge should resist in taking any step which would have the effect of shortening Ms X's life. Counsel for Ms X, in his cross-examination of the medical witnesses, encouraged the judge to consider the potential benefits to Ms X of long-term in-patient treatment

for her anorexia – such a measure had the associated benefit that throughout such period of treatment, Ms X would have reduced access to alcohol. However, the medical experts could not accept that in-patient re-feeding treatment would bring real long-term benefits to Ms X unless within that period of treatment she was brought round to the idea of engaging in talking therapy. Each expert regarded that prospect as 'vanishingly low'.

Evidence presented by Ms Y showed however that Ms X retained an interest in life and had plans for her future, including 'visiting places', spending time with her beloved grandfather, distance learning and music. It was clear to Cobb J that although Ms X did not want to be compelled to receive treatment, she had no wish to die.

The judge was referred to several cases, including the *Bland* case cited above, as well as the decision of the Supreme Court in *Aintree University Hospital NHS Foundation Trust v James* [2013]. Baroness Hale noted that the starting point is that there is a strong presumption that it is in a person's best interests to stay alive but that this is not absolute, and that there are cases where it will not be in a patient's best interests to receive life-sustaining treatment. She commented that the decision-maker must look at the welfare of the individual concerned in the widest sense; the decision-maker should take into account not just medical factors but also social and psychological factors and that:

> ... they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be.

The judge considered that a hospital admission would impose a considerable restriction on Ms X's liberty, interfere with her rights under Article 8 ECHR and reduce her quality of life by removing her from the company of those closest to her (Ms Y and her grandfather in particular). At para 42, the judge observed the anomaly in this case:

> Medical treatment is invariably designed to achieve the protection and preservation of life. But there is a paradox in this case: that if I were to compel treatment, I may (and the doctors strongly argue that I would) be doing no more than facilitating or accelerating the termination of her life. I have no jurisdiction to make 'best interests' decisions about Ms X's drinking; that remains wholly within her power. Any treatment for her anorexia (particularly if that is in-patient and compelled) is likely – on past experience – to provoke subsequent, increased, sustained and dangerous alcohol consumption which will (in the medical view) hasten Ms X's death.

Further on in his judgment, Cobb J acknowledged that the paradox extended further; the medical professionals and Ms Y considered that if Ms X retained her autonomy, she may well access medical help, even if only of a palliative nature. He further considered that there were a range of other factors that weighed against compelling Ms X to undergo medical treatment. The very process of admitting her and compelling her to re-feeding would be highly traumatic for her. Further, if she were resistant (and there was good reason to believe she would be), this would inevitably require a degree of restraint which would, as it had in the past, cause her considerable distress. Articles 3 and 8 ECHR were in play where there was repeated force feeding over a long period of time against her clearly expressed wishes. There were other hazards present as well; the combination of liver disease and previous naso-gastric feeding treatments had led Ms X to suffer from varicose veins in her throat.

In accordance with the best interests checklist, Cobb J also took into account Ms X's own wishes and feelings that had been elicited through a number of professionals as well a letter written by Ms X herself, sent to the Official Solicitor on the eve of the hearing. The judge paid particular attention to the evidence of Ms Y who in the judge's view brought 'extraordinary wisdom, compassion, objectivity and insight into the current dreadful situation affecting her closest friend'.

Cobb J concluded that the relief sought by the Trust was in Ms X's best interests but it is clear that the decision was not an easy one. He was reassured by the fact that it was not just those who knew Ms X well who had concluded that such a decision would be in her best interests, but that it was also the view of Dr Glover (who was the independent and jointly instructed expert) who had advised the court in three similar cases in the past.

As Cobb J found, 'this is an unusual and desperately sad case' in which the court's obligations under Article 2 had to be weighed against Articles 3 and 8. However, Cobb J's enlightened judgment has upheld the freedom of the individual even though conventions of society militated against such an approach. Cobb J concludes:

> So far as I can do so, I have endeavoured to put myself in the place of Ms X, and guided by what she has directly told me and others, I have considered what her attitude to the treatment is or would be likely to be. Having fully reviewed the circumstances of the case, and for the reasons discussed above, I have reached the clear conclusion that I should not compel treatment for Ms X's anorexia.
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> I hope that Ms X will nonetheless realise that it will be of enormous benefit to her to access treatments (at least in the form of palliative care, nursing support and dietetic guidance) which may improve the quality of the limited life she has left to her, if not to render more dignified its passing. ■

Baroness Hale noted that the starting point is that there is a strong presumption that it is in a person's best interests to stay alive but that this is not absolute.

Aintree University Hospital NHS Foundation Trust v James
[2013] UKSC 67
Airedale NHS Trust v Bland
[1993] AC 789
A NHS Foundation Trust v Ms X
[2014] EWCOP 35 (to be reported in a future edition of *WTLR*)