NB: A REPORTING ORDER IS IN FORCE TO PROTECT THE IDENTITY OF THE SUBJECT OF THE PROCEEDINGS AND HER FAMILY. THE INFORMATION IN THIS JUDGMENT CAN BE PUBLISHED PROVIDED THAT THE ORDER IS COMPLIED WITH.

IMPORTANT NOTICE

This judgment was handed down after a hearing in public. It can be reported provided that the terms of a reporting restriction order made on 26 February are complied with. That order prevents the identification of Miss W and her family, the hospital in which she is being treated and the staff who are caring for her. Failure to comply with the order may be a contempt of court.

Case No: COP12819431

Neutral Citation Number: [2016] EWCOP 13

IN THE COURT OF PROTECTION

26 February 2016

Before :

THE HONOURABLE MR JUSTICE PETER JACKSON

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Between :

Betsi Cadwaladr University Local Health Board **Applicant**

-and-

Miss W (by her litigation friend, the Official Solicitor) **Respondent**

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Andrew Bagchi QC for the Applicant Trust

David Lock QC instructed by the Official Solicitor for Miss W

Miss W's mother and sister appeared in person

Hearing dates: 24 – 26 February 2016

Judgment date: 26 February 2016

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JUDGMENT: Re W (Medical Treatment: Anorexia)

JUDGMENT

Mr Justice Peter Jackson:

Introduction

1. Anorexia nervosa (from the Greek *an-/without –orexia/appetite*) is a pernicious condition. In its severe form it is life-governing and potentially fatal. In order to stay alive, a human being needs air, water and food. The normal energy intake for an adult woman is about 2000 calories a day. A healthy Body Mass Index (BMI) is between 18.5 and 25. If the body uses more energy than it gains over a prolonged period, the result is malnutrition, with a global effect on well-being. The physical consequences can include endocrine disorder preventing the onset of puberty, slow heart rate, low blood pressure, hypothermia, anaemia, reduction in white blood cells, reduction in bone density and reduced immune system functioning. The social consequences for individuals and their families can be devastating, as they damage or destroy normal social development. The psychological consequences for the sufferer include a mental life dominated by thoughts of food. The act of eating is all too easy for most people in developed societies. But for the sufferer, whose life would be utterly transformed by the most modest food consumption, the ability to eat is seemingly overpowered. Years are spent thinking and talking about eating, but talking about eating is not the same thing as eating.

2. In this case, Miss W, a young woman aged 28, has suffered from a severe and enduring eating disorder for 20 years, with physical, social and psychological consequences of the kind described above. In this judgment I will call her W. Since the age of 11, she has had six admissions for inpatient treatment, spread between five units around the country and amounting to about 10 years in total. Her current admission has lasted for 2½ years and yet, despite the most intensive support, she is barely eating and is losing weight at the rate of 500 g – 1 kg per week. She now weighs less than 30 kg and her BMI is 12.6. If she continues to lose weight at this rate, she will die.

3. In the circumstances, her local health board has brought these proceedings in the Court of Protection as a matter of urgency. They were issued on 3 February, and directions were given on 10 February for this hearing, which has taken place on 24-26 February.

4. I have read reports from many of the medical professionals who have treated W, statements from W herself and from her parents and sister, and reports from Dr Tyrone Glover, the psychiatrist instructed by the Official Solicitor on behalf of W. I have spoken with W herself by video-link and have heard evidence from her responsible psychiatrist, Dr X, from Dr Glover and from W's mother and sister. After

receiving closing submissions from Mr Andrew Bagchi QC for the Health Board, and Mr David Lock QC for W, instructed by the Official Solicitor, I gave my decision on 25 February with brief reasons, which I expand upon in this judgment. W said that she would like to speak to me again after the decision had been made, and I have done that.

5. The outcome is that, accepting the unanimous professional view, I approve the plan of the Health Board. This is that W should now be discharged into the community with a closely thought-out package of support for her and her family. Given W's fragile condition, it is a plan that has only been arrived at after the most anxious consideration by her care team. It will at first seem counterintuitive that someone so ill should be discharged from hospital. The conventional assumption is that hospital treatment is likely to bring benefits, but the evidence has persuaded me that in this case that is not so. The outcome is to some extent in accordance with W's wishes, which I will describe below.

The law

6. There is a strong but not absolute presumption that it is in a person's best interests to receive treatment that helps her to stay alive. There may be circumstances in which the treatment is not in the person's best interests, perhaps because it is futile or unduly burdensome.

7. In Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWCOP 1639 at paragraphs 11 – 15, I set out and do not repeat the statutory framework under the Mental Capacity Act 2005 and the terms of Articles 2, 5 and 8 of the European Convention on Human Rights.

8. These statements of principle are equally applicable in the present case:

"People with capacity are entitled to make decisions for themselves, including about what they will and will not eat, even if their decision brings about their death. The state, here in the form of the Court of Protection, is only entitled to interfere where a person does not have the capacity to decide for herself.

By contrast, where a person lacks capacity, there is a duty to make the decision that is in her best interests.

The first question therefore is whether the person has capacity. The second, which can only arise if she does not, is what decision is in her best interests."

9. The proper approach has now been considered by the Supreme Court in Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67, where Baroness Hale said this:

"The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; 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; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

The background

10. W's family consists of her parents, her younger sister and her grandmother. In 2015, W obtained the tenancy of her own flat, not far from her parents, but in the circumstances she has hardly occupied it.

11. W has suffered from difficulties in her mental health since she was very young. At the age of seven, she was diagnosed to have obsessive-compulsive disorder and by the age of 10, anorexia nervosa. She has been an inpatient on six occasions at these ages and for these periods of time:

Age 11	18 months
Age 13	15 months
Age 17	18 months
Age 19	9 months
Age 22	17 months
Age 25	2½ years

Three of the five units concerned are specialist eating disorder units (SEDUs). The current placement is a psychiatric unit rather than an SEDU, but I accept that the treatment that W has received there is very comparable.

12. Unfortunately, none of these periods of treatment has led to W making enduring progress. In 2006, when (aged 19) she was discharged weighing a relatively healthy 43 kg, but three months later she was detained under the Mental Health Act with a weight of 31 kg. Following this episode, a period of some stability was achieved, during which W was able to spend over a year at university. However at the age of 22,

she was admitted in an emergency weighing 25 kg, with a BMI of 10.8. After this substantial admission, she was discharged weighing 32 kg.

13. The current admission began when W was 25. She was again admitted in an emergency and placed under section. Attempts to build up her strength and return her to the community were unsuccessful. On one occasion of leave, W lost 3 kg in three days. Subsequently she achieved a BMI of 16, her highest in 10 years, but during another period of community leave she had to be readmitted in an emergency after losing 9 kg.

14. By the end of 2015, the relationship between W and Dr X had become strained on W's part. W had obtained the possibility of a job but Dr X had had to inform the employer that she was quite unfit to work. W accepted this but considered that Dr X should not have intervened. In agreement with Dr Glover, I feel that Dr X had no alternative.

15. At all events, W has been steadily losing weight on the unit, dropping from 34 kg in December to 32 kg in January, and she is now significantly under 30 kg, as described above. She achieves weight loss by declining food and by over-exercising, if this is not prevented.

16. W is currently subject to detention under s.3 of the Mental Health Act.

17. In her statement, Dr X describes the repetitive pattern of events: initial engagement for 1–2 weeks – initial small improvements – collaborative approach adopted – boundaries challenged – treatment begins to fail – frustration increases – weight drops – pattern continues for months/years – transfer to another team/consultant – whole pattern repeats itself – no further forward – W becomes more ill for longer – every time the endpoint becomes less favourable.

18. In her report, Dr X says this:

"I honestly can say that in my opinion we have tried everything that we can to enable W to gain and maintain her weight. This has been tried in inpatient settings, outpatient setting, specialist eating disorders units, informally and under detention, using minimal force and restraint to using maximum force and restraint, using NG tube feeding and solid food intake and a combination of both of them."

The application

19. After considerable consultation and a number of best interests meetings, the Health Board issued proceedings. It raised two contrasting proposals for consideration.

20. The first proposal was for W to be re-fed under sedation. This would involve her being rendered unconscious for up to 6 months and fed by tube until she gained a BMI of 17.5. This proposal has not been pursued, rightly in my view. It is an unprecedented step and there were numerous potential objections about its ethical basis, W's objections, the unavailability of clinicians to carry it out, and the improbability that it would bring about sustainable change. By the time this hearing began, the proposal was by common consent off the table.

21. The second option involves a recognition that W's condition is not currently treatable and that her remaining on an acute ward is not appropriate. It entails an immediate discharge to her parents' home and her flat with a full community support programme, details of which are set out in Dr X's second statement at paragraphs 12 and 13.

22. The only other option that has been considered is the possibility of W being admitted to another SEDU for a short period of weeks before going into the community. Alternatively, her remaining in the current unit for several weeks to see if she can gain weight before discharge.

23. There is a unanimous professional view that using coercion to get W to eat is no longer appropriate.

24. The Official Solicitor's representative Ms Breathnach and his counsel Mr Lock QC met W on 15 February. His expert, Dr Glover, who had previously met her in December, met her again on 18 February.

25. The Official Solicitor accepts Dr Glover's advice as to W's best interests and supports the Board's application.

The evidence

26. I accept the advice of Dr X and Dr Glover that W, by reason of her severe anorexia, lacks the capacity to make decisions about the care and treatment of the condition, though she does have capacity to make other decisions, including decisions about her physical health.

27. W's best interests therefore have to be identified with reference to the considerations in s.4 of the Act.

28. Firstly, I have regard to W's wishes and feelings and her beliefs and values. W does not want to die. She would like to return to education and has a career path in mind. Unfortunately she is so far from being fit to resume this course that it is scarcely a realistic one at present.

29. W has provided two documents setting out her position. They are remarkable for their clarity and analytical nature. They also have a detached quality that speaks of W's long years of focusing on the issue of her eating. However, there is no mistaking the sincerity of her description of her current situation: *"Currently I am struggling because I have no control over decisions in my life. I have no focus on things I would like in life that I am being denied. I see no light at the end of the tunnel and am extremely anxious over what is going to be decided."*

30. When I spoke to W two days ago, I asked her what was the most important thing for her. She replied: *"To make my own decisions and that treatment should not be enforced*". She would like to go home and feels that she could *"turn it round"* and that, having been *"rescued"* all her life, she has never tried to manage on her own. She acknowledges that it would be a huge task, carrying the risk of death, and says that if it didn't work after a couple of weeks, she would like to have a short re-admission to the unit or, preferably, to an SEDU. On the current unit, she feels that she has failed and that nobody believes that she can succeed. The loss of the prospect of a job hit her hard. She wants support, not a battle. She would like what she described as a collaborative plan.

31. I asked W about the nature of anorexia. Does she feel that it is a mental disorder or, as some have suggested, a condition in the nature of an addiction? Her insightful response was that some aspects of her behaviour, notably exercise, was like an addiction, but that the overall condition was more a way of life.

32. There is an obligation upon any decision-maker to encourage a person to participate as fully as possible in any decision affecting her: MCA s.4(4). W was not well enough to come to London for the hearing, but I hope that the opportunity to put her point of view in her own way will have been helpful to her, as it has been to me.

33. The opportunity to talk to W, even by video-link, did not reveal new information – her position is exhaustively described in records of the endless series of discussions she has had with others – but I valued the opportunity to meet her and to understand her point of view as clearly as possible. The proceedings have been stressful for her (she described herself as feeling lost) and I greatly admire the composed way in which she was able to discuss her predicament.

34. I turn next to the views of W's carers and her family.

35. W's mother and younger sister have been deeply involved in the efforts to help and support her. They both have a close understanding of the issues and participated in the hearing with dignity, raising a number of important issues for the doctors who gave evidence. They point to a time, some 10 years ago, when they feel that W might have made real progress if inpatient treatment had continued for longer. They are also acutely apprehensive about what a discharge from treatment would mean for W now, and for them as a family. (This point of view is expressed, somewhat more strongly, by W's father who by his own description has taken more of a back seat.) That said, the only difference of emphasis between the family and the doctors is that the family members tend to support W's suggestion that consideration is given to a period of a few weeks being allowed to prepare for discharge, either from the current unit or from an SEDU.

36. It was moving to observe the obvious love, commitment and concern that W's mother and sister feel for her, and the way that they supported each other during this difficult hearing. I attach considerable weight to their point of view.

37. There is a wealth of information and opinion in reports from the many medical professionals who have worked closely with W over the years, specifically:

Mr P, mental health nurse, who has known W since 2006
Ms F, mental health nurse, who has known her since 2006
Ms W, community psychiatric nurse, who has known her since 2006
Dr R, clinical psychologist 2011 – 2013
Dr H, clinical psychologist 2011 – 2014; she saw W again on 27 January
Ms R, eating disorders practitioner 2011 – 2014
Mr R, occupational therapist since 2014
Ms L, dietician since 2015
Dr E, W's current clinical psychologist
Ms C, W's current named nurse

38. To give the flavour of the consistent theme from this evidence, I extract these observations from the reports of the three psychologists:

Dr R: *"W associated the eating disorder with the means of keeping people close and receiving care. She was fearful that others wouldn't care about her as much without it."*

Dr E: *"… There were very difficult feelings associated with the actual process of eating. W said she feared these feelings which is why she resisted eating. The feelings chiefly seemed to be those of guilt and remorse. Clearly then, the process of eating had become something almost sinful… She told me (and I had no sense that she was being disingenuous) that she wanted a future without anorexia… Having had problems with food since she was 10 years old, anorexia had become a huge part of her identity. W was aware of this. It was not only difficult for her to imagine a life without it, it was also a little scary. Take away the anorexia and what was left?"*

Dr H: *"W was very similar in presentation to the last time I saw her over 2 years ago. She has entrenched anorexia nervosa thoughts and behaviours that seem to be virtually impossible for her to fight… Sadly, psychologically I saw little change since I last worked with her… Foremost for all the treating team has been the sustaining of life. W is only 28 years old, with potentially many years ahead of her. However, in my view the picture is a very complex one. If the pattern continues as it has been for W, we have potentially a young woman who could spend the rest of her life in hospital, distressed and angry at having all self-determination, autonomy and control taken away. This will have subsequent impact on her quality of life and ethical as well as practical implications… After 18 years duration, sadly my opinion is that it is very unlikely W is going to make a significant recovery… In my view, over the years some iatrogenic factors could have potentially crept in, in terms of W's relationship with services and others around her… NHS clinical staff have become her main social connections… Services can become a reinforcing influence by providing an overly protective environment which ensures safety and security while reducing loneliness and isolation. This limits the need for an individual to develop their own sense of responsibility, autonomy and independence. Also, the highly structured environment of inpatient care supports the rigid attention to detail and inflexibility which is characteristic of people with eating disorders, allowing these negative behaviours to thrive…"*

39. I turn to the evidence of Dr X and Dr Glover. By the time they had completed their evidence, a broad consensus had emerged.

40. Dr X said that she had been involved in W's care for four years and intensively for the last 2½ years. She confirmed that she would immediately discharge W from compulsory detention because, while her condition warrants treatment, they have found no way of treating it. If W is to stay on the ward, there needs to be a treatment plan and a goal. It is not otherwise possible for an acute bed to be held open. The decision to discharge W into the community has received the utmost consideration. There may only be a glimmer of hope that the change in circumstances will lead to a change in thinking and behaviour. However, in Dr X's opinion, the alternatives are

worse. She does not believe that life on the unit is a life for W, who anyway does not want to be there. It would be a continuation of what has been happening for the last 20 years, which hasn't worked. As to the prospect of a move to another unit, assuming one could be found, that would be cruel because the prospects of change are so remote.

41. Dr X accepted that in its own way the option that she now proposes is as momentous as the force-feeding option that she no longer proposes. She was asked about the element of her plan which states that W will not be readmitted to the unit, even in an emergency, unless there is a reason to think that there has been a real change in her treatability. In such circumstances, W would be treated on a medical ward and any decisions would have to be taken in that context.

42. Dr X considers that a discharge into the community, while very likely to lead to further deterioration in W's condition, would at least give her the opportunity to exercise any control that she is capable of exercising over her condition. She was unable to identify any viable collaborative plan involving a promise of readmission in the current circumstances.

43. On the crucial question of the prolongation of W's life, Dr X did not think that remaining on the unit would be more likely to prolong life than any other alternative.

44. I found Dr X to be a most impressive witness who had thought long and hard about the welfare of her patient and the options that are truly available in this intensely difficult situation. Questioned about a number of "softer" options, such as a move to another unit or a postponement of the discharge, she responded convincingly. Although she has previously proposed other options (feeding under sedation, imposition of a DNACPR notice) that had understandably caused real concern for W and her family, by the time Dr X came to give evidence, I found her to be flexible in her thinking but clear in her conclusions. I accept her evidence.

45. Dr Glover is a psychiatrist specialising in eating disorders. He has advised in similar cases and once again his formulation has been of great assistance. He confirms that W has severe and unremitting anorexia from which she has never enjoyed a period of remission. He considers that coercion is no longer justified and that after such a long course of illness a cure is not to be hoped for. The early age of onset, the resistance to treatment, the distortion of personality, and the lack of insight are all negative prognostic factors. The best that could be achieved is a limited degree of recovery and the maintenance of that state. He thinks that a move to an alternative unit while matters remain as they are would be very likely to be futile. If progress (by which he means no more than a significant period of limited deterioration) could be made, that

possibility might be reconsidered, but it is not worth pursuing as matters stand. If W was now admitted elsewhere as a voluntary patient, the chances of her being able to start eating sufficiently would in his view be nil and the process would be unwise and unfair. Likewise, there would be no real benefit to W in postponing her discharge from the unit for a few weeks.

46. Dr Glover was guarded about any therapeutic intervention turning W's situation around. At the moment she understands intellectually that her life is already in danger but she is not overly concerned at the prospect. The history shows that W only eats when her situation deteriorates to such an extent that she actually believes that she might be in imminent danger of death.

47. Dr Glover's advice was clear and practical, and I accept it.

Conclusion

48. Whether or not she fully realises it, W's situation is exceptionally worrying and her options are very limited. This hearing has in effect been a search for a less drastic outcome than those with which the court was originally presented. Assisted by all parties, I have looked to see whether there is a realistic alternative to the Board's proposal. In agreement with the doctors and medical staff, and also to a significant extent with W and her family, I have concluded that there is not. After all that has happened, it now has to be accepted that it is beyond the power of doctors or family members, and certainly beyond the power of the court, to bring about an improvement in W's circumstances or an extension of her life. The possibility that the withdrawal of inpatient mental health services will bring about a change for the better may not be very great, but in my judgment it is the least worst option from W's point of view.

49. Particularly when considering the situation of such an able and likeable young person as W, the judicial instinct (so described by Cobb J in A NHS Foundation Trust v Ms X (By Her Litigation Friend, the Official Solicitor) [2014] EWCOP 35) is strongly directed to giving the highest priority to the preservation of life. If any available option offered the prospect of a significant extension in W's lifespan, I would naturally look at it with favour. However, that is not the case here.

50. I recognise that W has been in an institutional environment for so long that it is there that she is most truly at home. For her to leave the ward means the loss of the close ties that she has with the clinical staff and of the rules-based setting in which she has mostly lived. Hard as it is to accept, I nonetheless agree that this environment,

designed to be therapeutic, is not therapeutic at all for W. It has become a place for talking about eating, and not for eating. If she is capable of making any progress, it will not be as an inpatient.

51. It should therefore be stressed that this is absolutely not a situation where necessary services are being withdrawn from W. No one is giving up on her, but the present treatment, such as it is, is not beneficial and it is therefore not right for it to continue.

52. W and her family are understandably anxious that she will not be readmitted to the unit if she deteriorates. As to that, I stress that in approving the order I am only endorsing the Board's plan in relation to the circumstances as they now exist and for so long as they continue. The court can only make decisions in relation to existing circumstances or circumstances that it can foresee with reasonable confidence. It is accordingly accepted by the Board that if a significant period of time passes, accompanied by signs that W's thinking and behaviour have been able to change, the normal ethical and legal obligation upon the health services to reassess the situation will exist. In brief, the Board is saying "not now"; it is not saying "not ever", and it is that outcome that the court is endorsing.

53. In the meantime, the Board will be under a duty to provide the community services that it has promised and I know that Dr X will make good on that promise.

54. I know that W understandably considers that she has in some way failed. I certainly do not see it that way. To be faced with such a severe illness from such a young age is not a failure but a misfortune. W and her family now face a daunting future. They know that it will be a huge task for W to live in the community and that the chances of real change are unlikely, but they will be the last to lose hope. Unlikely things happen all the time and if any family deserves some good fortune it is this one. I earnestly hope that things go as well as they can for W, who has so many good qualities if her illness will only let her be.