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Case No: 12153212

Neutral Citation Number: [2012] EWHC 1639 (COP)

IN THE COURT OF PROTECTION

IN THE MATTER OF THE MENTAL CAPACITY ACT 2005

Royal Courts of Justice

Date: 15 June 2012

Before :

THE HONOURABLE MR JUSTICE PETER JACKSON

Between :

A Local Authority

Applicant

- and -

E (by her Litigation Friend the Official Solicitor)

- and -

A Health Authority

- and -

E's Parents

Respondents

Paul Bowen QC and Stephen Broach (instructed by Local Authority Legal Solutions)
for the Local Authority

Christopher Johnston QC and Susanna Rickard (instructed by the Official Solicitor)
for E

Mark Mullins (instructed by Legal and Risk Services) for the Health Authority
E's Parents represented themselves

Hearing dates: 25 & 28 May 2012

JUDGMENT

Mr Justice Peter Jackson:

Introduction

1. E is a 32-year-old woman who suffers from extremely severe anorexia nervosa, and other chronic health conditions. On 18 May 2012, an urgent application was made to the Court of Protection by her local authority, which was concerned that her position should be investigated and protected. E's death was imminent. She was refusing to eat, and was taking only a small amount of water. She was being looked after in a community hospital under a palliative care regime whose purpose was to allow her to die in comfort.
2. A hearing took place on 25 and 28 May, at which E was represented by the Official Solicitor, the other parties being her parents, the local authority and the health authority.
3. At the end of the hearing, I gave my decision with brief reasons. I found that E lacked capacity to make a decision about life-sustaining treatment and declared that it was in her best interests to be fed against her wishes with all that this entails. I now give fuller reasons for what was a very difficult decision.
4. There are established instances of the withdrawal or withholding of life-sustaining treatment from people in a permanent vegetative state who have no degree of awareness. There are also a few cases in which treatment or continued treatment has been found not to be in the best interests of very young or very elderly patients suffering from incurable terminal illness.
5. E's case has raised for the first time in my experience the real possibility of life-sustaining treatment not being in the best interests of a person who, while lacking capacity, is fully aware of her situation. She is in many ways the opposite of a PVS patient or a person with an inevitably fatal condition. She is described as an intelligent and charming person. Albeit gravely unwell, she is not incurable. She does not seek death, but above all she does not want to eat or to be fed. She sees her life as pointless and wants to be allowed to make her own choices, realising that refusal to eat must lead to her death. Her situation requires a balance to be struck between the weight objectively to be given to life on one hand and to personal independence on the other.
6. A further element of the situation is that in 2011 E twice attempted to make advance decisions refusing the treatment that is now proposed.

The law

7. 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.

8. By contrast, where a person lacks capacity, there is a duty to make the decision that is in her best interests.
9. 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.
10. A valid advance decision made at a time when a person has capacity will be effective if the decision has to be made after capacity has been lost.

The Mental Capacity Act 2005

11. These principles appear and are amplified in the statutory framework of the Mental Capacity Act 2005 ('the MCA'), the relevant provisions being ss. 1-4 and 24-26.

1 The principles

- (1) The following principles apply for the purposes of this Act.*
- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.*
- (3) 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.*
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.*
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.*

2 People who lack capacity

- (1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.*
- (2) It does not matter whether the impairment or disturbance is permanent or temporary.*

- (3) *A lack of capacity cannot be established merely by reference to—*
 - (a) *a person's age or appearance, or*
 - (b) *a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.*
- (4) *In proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.*
- (5,6) ...

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).*
- (2-4) ...

4 Best interests

- (1) ...
- (2) *The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.*
- (3) *He must consider—*
 - (a) *whether it is likely that the person will at some time have capacity in relation to the matter in question, and*
 - (b) *if it appears likely that he will, when that is likely to be.*
- (4) *He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.*
- (5) *Where the determination relates to life-sustaining treatment he 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.*
- (6) *He must consider, so far as is reasonably ascertainable—*

- (a) *the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
 - (b) *the beliefs and values that would be likely to influence his decision if he had capacity, and*
 - (c) *the other factors that he would be likely to consider if he were able to do so.*
- (7) *He must take into account, if it is practicable and appropriate to consult them, the views of—*
- (a) *anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,*
 - (b) *anyone engaged in caring for the person or interested in his welfare,*
 - (c) *any donee of a lasting power of attorney granted by the person, and*
 - (d) *any deputy appointed for the person by the court,*
- as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).*
- (8-11) ...

24 Advance decisions to refuse treatment: general

- (1) *“Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—*
- (a) *at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and*
 - (b) *at that time he lacks capacity to consent to the carrying out or continuation of the treatment,*
- the specified treatment is not to be carried out or continued.*

(2-5)...

25 Validity and applicability of advance decisions

- (1) *An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—*
- (a) *valid, and*
 - (b) *applicable to the treatment.*

- (2) *An advance decision is not valid if P—*
- (a) *has withdrawn the decision at a time when he had capacity to do so,*
 - (b) *..., or*
 - (c) *has done anything else clearly inconsistent with the advance decision remaining his fixed decision.*
- (3-4) ...
- (5) *An advance decision is not applicable to life-sustaining treatment unless—*
- (a) *the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and*
 - (b) *the decision and statement comply with subsection (6).*
- (6) *A decision or statement complies with this subsection only if—*
- (a) *it is in writing,*
 - (b) *it is signed by P or by another person in P's presence and by P's direction,*
 - (c) *the signature is made or acknowledged by P in the presence of a witness, and*
 - (d) *the witness signs it, or acknowledges his signature, in P's presence.*
- (7) ...

26 Effect of advance decisions

- (1) *If P has made an advance decision which is—*
- (a) *valid, and*
 - (b) *applicable to a treatment,*
- the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.*
- (2-3)...
- (4) *The court may make a declaration as to whether an advance decision—*
- (a) *exists;*
 - (b) *is valid;*
 - (c) *is applicable to a treatment.*
- (5) ...

12. The MCA requires the court to approach its task in a highly individualised way, focusing on the situation of the individual concerned and not on generalities.

The Human Rights Act 1998

13. By virtue of the Human Rights Act 1998 s.3(1), the court must so far as possible read and give effect to the MCA in a way which is compatible with the European Convention on the Protections of Human Rights and Fundamental Freedoms 1950. Relevant rights under the Convention are those contained in Articles 2,3, 5 and 8.

ARTICLE 2 RIGHT TO LIFE

1 Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

2 ...

ARTICLE 3 PROHIBITION OF TORTURE

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

ARTICLE 5 RIGHT TO LIBERTY AND SECURITY

1 Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(a-d) ...

(e) the lawful detention ... of persons of unsound mind...;

2-5 ...

ARTICLE 8 RIGHT TO RESPECT FOR PRIVATE AND FAMILY LIFE

1 Everyone has the right to respect for his private and family life, his home and his correspondence.

- 2 *There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.*
14. A comprehensive survey of the law relating to the withdrawal or withholding of life-sustaining treatment has recently been carried out by Baker J in [W v M & Ors \[2011\] EWHC 2443 \(COP\)](#) at [57]-[103]. I draw attention to paragraph [77], in which he lists cases where life-sustaining treatment has been withheld or withdrawn in non-PVS cases, none of which resemble E's case.
15. The provision of artificial nutrition and hydration is a form of medical treatment: MCA Code of Practice 9.26.

E's history

16. Except in one very important respect, E had a happy early childhood. She has two sisters who are both in long-term relationships and now have young children. Unhappily, and unknown to her parents until many years later, E was seriously sexually abused between the ages of 4 and 11. At the age of 11 she began to control her eating and from the age of 12 or 13 she started binge eating with self-induced vomiting, and also began to use alcohol. At the age of 15, her weight had dropped to the point that she was admitted for nine months to a specialist unit for the treatment of adolescent eating disorders. This was successful in the short term and, although her weight remained low, she was able to complete her schooling satisfactorily and go to university to study medicine, where for several years she achieved highly in a demanding course. She then became involved in a bad relationship and began drinking heavily. She had to drop out of her medical training, but went travelling with a new boyfriend in what she remembers as a very happy time in her life. However, in early 2006 she was again admitted for inpatient treatment and thus began a continuous series of emergencies and admissions that have now lasted for six years.
17. During this time, E has had placements in four specialist eating disorder units and one alcohol treatment unit. These lasted respectively for three months, three months, five months, eighteen months and two months. Between 2006, when she was aged 26, and the middle of 2010, when she was aged 30, E spent more than half of her time in one or other of these placements. In the past two years, she has mostly been treated in her own flat in the community as a result of the failure of the residential placements and the unavailability of further funding. This has led to a 'revolving door' series of emergency admissions for medical and psychiatric care, often after she was found in a

collapsed state after drinking as much as a bottle of spirits a day. Indeed, alcohol has for some time represented her only source of calories. She has been placed under compulsory Mental Health Act section on about 10 occasions, including for one period lasting for almost 4 months.

18. In the meantime, her relationship with her boyfriend, who had effectively become her carer, came to an end in 2008. He formed a new relationship and has since married. A further blow for E was the loss of a friend in a road accident in 2010.
19. Over the course of the last two years, E has thought a great deal about making an advance decision about her medical treatment, with a view to preventing others feeding her. At various times she has been regarded by her doctors as having the capacity to do this, while other doctors have taken a different view.
20. At all events, in July 2011, E signed a document saying that she did not want to be resuscitated or to be given any medical intervention to prolong her life. In October 2011, she signed another advance decision in a standard form, assisted by her mother and her mental capacity advocate. On the same day, she was detained under Section 3 of the Mental Health Act 1983 ('the MHA') and the day after that she was admitted for a two week assessment by Professor L at an eating disorder unit. He expressed the view that her anorexia had moved into a severe and enduring phase but that she could benefit from treatment.
21. Following E's return to the community, the familiar pattern reasserted itself. In early 2012, she was again drinking very heavily, with crises requiring hospital admissions. On 20 March, she was again detained under Section 3 of the MHA. She was initially fed by tube, but opposed this and tube feeding was stopped. As a result, she has not been taking any calories at all since the end of March. On 3 April, a meeting between all the professionals and E and her parents reached the unanimous view that all treatment options have been exhausted. On 20 April, she was admitted to the community hospital for palliative care and placed on an 'end of life' care pathway with high doses of opiate medication, to which she is physically addicted.
22. Although E has in the past been compulsorily treated under the provisions of the MHA, she is not currently subject to detention and the issues that arise have been brought before the court for decision under the terms of the MCA.

E's medical conditions

23. Dr Tyrone Glover is a consultant in eating disorder psychiatry, and an expert in very severe eating disorders, of which E's case is an extreme example. He

was commissioned to report by the Official Solicitor. He advises that E suffers from (1) severe anorexia nervosa, (2) unstable personality disorder, borderline subtype, (3) alcohol dependence syndrome, (4) opiate dependence, and (5) the debilitating and lifelong physical consequences of long-term malnutrition.

24. Dr Glover describes E's condition as extraordinarily complex. The triad of anorexia, alcoholism and personality disorder are extremely rare, but not unheard of, in the UK. It is this mixture of conditions which has, at least so far, made her so difficult to treat. If she were restored to a reasonable weight, this would not by any means represent an overall recovery. Rather, it would be a precondition for starting on fundamental psychological and physical therapies.
25. E's extremely low weight can be seen from her Body Mass Index (BMI) measurements. A healthy BMI figure is in the region of 20. A figure of less than 17.5 is in the anorexic range. A figure of less than 14 represents dangerous and severe weight loss. A figure of less than 12 indicates an increased risk of sudden cardiac death. During the course of the past four years, E's BMI has remained well below 14. For the past 2 years or so, it has been in the region of 11 or 12, and when last measured it was 11.3.
26. Anorexia nervosa is a pervasive psychiatric illness in which the sufferer has a grossly distorted perception of her correct body shape. Cardinal features are a morbid fear of weight gain, with behaviour aimed at weight loss, and amenorrhoea (absence of menstrual periods). A person such as E, with anorexia of the most severe and intractable kind, is incapable of recovery without major medical intervention. Paradoxically, the determination to avoid food increases as the sufferer's physical condition worsens. Some with severe condition will stabilise at a BMI of 13/14 and engage with treatment. Others, such as E, have (as Dr Glover put it) "*no parachute*".
27. A significant feature of E's personality disorder is associated with difficulties in forming and maintaining relationships.
28. E has been abusing alcohol since adolescence as a means of escape. It is an unfavourable complicating feature in relation to her prospects of recovery.
29. E's physical addiction to medically prescribed opiates has developed over a number of years, and would require a controlled withdrawal programme
30. All this has had a profound effect on E's physical health. She has not taken solid food for more than a year. Due to impaired nutrition, she suffers from osteoporosis, meaning that her bone density is extremely low. In September 2011, she had to have a hip replacement operation, which was followed by

complications. Her mobility is extremely reduced, to the point where she always requires support to move about and often requires a wheelchair. She may now be infertile. It is impossible to say what effect her physical and mental condition has had on her life expectancy, but if she were to survive her current predicament, it is likely that her overall life expectancy is reduced.

The proceedings

31. The local authority was concerned that E's position should be more fully investigated. On 18 May, it issued an application and directions were given at a hearing that day.
32. On 19 May, having heard that her case was before the court, E made a suicidal gesture by hanging herself from an emergency call cord in a bathroom, suffering no significant injury.
33. On 20 May, she spoke about her situation at length to the Official Solicitor's representative, Mr Mark Powell QC, and also more briefly to Dr Glover.
34. On 25 May and 28 May, the hearing took place, a weekend intervening. At the end of the first day, the Official Solicitor and the local authority invited me to make an order that E be moved to an intensive care unit, so that she could be fed to ensure that she did not die over the weekend. The parents did not support this. I declined to make an interim declaration as I did not consider it right to embark down the road of forcible feeding without knowing what long-term resources were available and how any programme was to be carried out; nor was I prepared to take that step ahead of a decision as to whether such a course would be in E's best interests overall.
35. During the course of the hearing, evidence was given by Dr Glover, by Dr C (E's consultant gastroenterologist and acute physician), by Dr D (E's consultant psychiatrist), and by Dr M, who would admit E for treatment at a specialist hospital referred to below. E's parents contributed significantly to the hearing without giving formal evidence, by giving their views and by asking well-chosen questions of the doctors.

The position of the parties

36. E's parents are highly sceptical about fresh professional promises and have grave misgivings about the likely outcome of further treatment. They do not want E to die, but after years of supporting her through a series of unsuccessful treatments they believe that unless further medical intervention has a real prospect of making a difference, her wishes should be respected. For E's sake, they dread another failed effort, followed by a return to the community without adequate support. They emphasise the long-term nature

of the problem and the very poor quality of life that E has had in recent years. They ask: if E survives, having been forced to eat, will she thank us in five years' time?

37. Speaking on behalf of the medical staff who have been looking after E, Dr C and Dr D were highly doubtful about further coercive treatment, but acknowledged the difficulty of the decision and offered to support whatever course was taken. The health authority itself adopted a neutral position. It did not mount a positive case against forcible feeding and will act in accordance with the court's decision, including by funding any treatment that is considered to be in E's best interests.
38. The Official Solicitor relies on the advice of Dr Glover. Dr Glover's preliminary impression after meeting E was that it was not in her interests to be forcibly fed. On reflection, and having studied her medical records, he advised that treatment which might return E to relatively normal life is available but has not so far been tried, and that she should receive it. The Official Solicitor accordingly sought a declaration that forcible feeding is in E's best interests.
39. The local authority, which brought the proceedings, was initially neutral but ultimately supported Dr Glover's proposal. It did not call evidence.

Timing and presentation of the application

40. E's case should have been brought before the court long before it was. Her condition has been seen by those treating her as raising an ethical predicament since at least 2009, if not before. As long ago as July 2011, the health authority considered referring the matter to the court in the context of doubts over the validity of E's advance decision. Apart from anything else, an earlier application might have allowed E herself to participate directly in the proceedings if she chose; as it was, her condition at the time of this hearing meant that this was not possible. It has also meant that the question of treatment has only been brought forward several weeks after E embarked down the palliative care pathway.
41. The other point that I would make is that in a case with legal, moral and ethical dimensions, it is important for the court to ensure that it is informed of the actual practical possibilities and not to be drawn into theorising. On the first day of the hearing, I was invited to reach a conclusion on the general principle of whether feeding E would be in her interests. I was not willing to engage in an exercise which was of no value without solid information about what treatment options were actually available. As a result, further inquiries were made and a meeting took place involving Dr Glover, Dr C, Dr D, Dr M and others. They drew up a detailed proposal for E's treatment if forcible feeding was found to be in her best interests.

The available options

42. In the event, there were two only possible courses of action.
43. The first was that there should be no intervention, with E remaining in the community hospital and being provided with care and pain relief until her death from the effects of starvation.
44. The second option was E's immediate transfer, via an intermediate hospital with an intensive care facility under the care of Dr C, to what may be the country's leading facility for the treatment of advanced eating disorders ('the specialist hospital') under the care of Dr M. She would be stabilised and fed with calorific material via a nasogastric tube or a PEG tube inserted through her stomach wall. Any resistance would be overcome by physical restraint or by chemical sedation. The process would continue for a year or more. Once her weight had been restored, she would be offered therapies for her eating disorder and for her other physical and psychological problems. By these means, she might overcome her feeling that life is not worth living.
45. There are, I find, no other realistic alternatives. The comforting prospect of E deciding to start eating of her own accord if the matter were left to her at such a late stage is in my view negligible. If she is not forcibly fed, she will die. Nor is some lesser form of intervention a practical solution. E has had numerous previous admissions for treatment for longer or shorter periods of time. These have not succeeded in the past and they would not succeed now.

The issues

46. I turn to the questions for decision, namely:
 - 1 Does E at this point have the mental capacity to make decisions about her treatment?
 - 2 If not, did she have mental capacity when she made an advance decision in October 2011, and is that decision valid and applicable?
 - 3 If she lacks capacity and has not made a valid advance decision, is it in her best interests to receive life-sustaining treatment in the form of forcible feeding with all necessary associated measures?

E's current mental capacity

47. E is presumed to have capacity unless the contrary is proved on the balance of probabilities: MCA ss. 1(2) & 2(4). She will lack capacity if at the material

time she is unable to make the treatment decision for herself because of an impairment of, or a disturbance in the functioning of, the mind or brain: MCA s. 2(1).

48. There is no doubt that E has an impairment of, or a disturbance in the functioning of, the mind or brain in the form of her anorexia. Equally it is clear that in terms of MCA s. 3(1) she can understand and retain the information relevant to the treatment decision and can communicate her decision.
49. However, there is strong evidence that E's obsessive fear of weight gain makes her incapable of weighing the advantages and disadvantages of eating in any meaningful way. For E, the compulsion to prevent calories entering her system has become the card that trumps all others. The need not to gain weight overpowers all other thoughts. By way of example, in August 2011, she was described as smiling and laughing during a conversation, but when the question of weight gain and the achievement of a BMI of 16 was mentioned, she began to cry.
50. A secondary reason for the conclusion that E lacks capacity is that she is now subject to strong sedative medication and is in a severely weakened condition. She is, as her parents described it, in a "drug haze".
51. I find that E lacks capacity in her current situation. I do not overlook the observation of the Official Solicitor's representative, Mr Powell QC, that in the absence of contrary medical opinion he would have felt able to take instructions from E, or of the opinions of Dr V and Dr D, recorded below, but I am clear that E's medical condition prevents this from being the ultimate conclusion.
52. I note Dr Glover's view that anyone with severe anorexia would lack capacity to make such a decision. To this, E's parents respond:

"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 to this, but not from the perspective of the sufferer who is not extended the same rights as any other person."
53. It is unnecessary to reach a conclusion about Dr Glover's general point, but 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.

E's advance decisions

54. Where there is a genuine doubt or disagreement about the validity of an advance decision, the Court of Protection can make a decision: MCA Code of Practice at 9.67. If ever there was a case where this route might have been taken, this was it.
55. I consider that for an advance decision relating to life-sustaining treatment to be valid and applicable, there should be clear evidence establishing on the balance of probability that the maker had capacity at the relevant time. Where the evidence of capacity is doubtful or equivocal it is not appropriate to uphold the decision.
56. On 24 July 2011, a doctor (Dr H) expressed the opinion that E had capacity, referring to the statutory test but not providing any deeper analysis.
57. On 25 July, E signed a note reading "*I do not want to be resuscitated or given any medical intervention to prolong my life.*" This was countersigned by her mother.
58. At the end of July, Dr E, a consultant psychiatrist expressed the view that E was not expressing a consistent and capacitous wish to die. E was placed under compulsory section (MHA s. 3). At the same time, her parents expressed doubts about her true intentions. Medical, social work and legal professionals were all confused about whether or not she had capacity in an area referred to in the notes at one point as "*a legal minefield*".
59. I am clear that E lacked capacity to make an advance decision on 3 July 2011. To an extent, this is confirmed by her subsequent attempt to put herself in a position to make an advance decision that would be accepted as valid.
60. In August and September 2011, E was either pulling out her PEG line or agreeing reluctantly to it remaining in, in the hope that she would achieve sufficient weight to be regarded as capable of making another advance decision.
61. On 3 October, E signed a formal advance decision, witnessed by her mother and a mental health professional, stating that if she was close to death she did not want tube feeding or life support, but would accept pain relief and palliative care. At the time this document was signed, her BMI had briefly peaked at 15.
62. I find that the s. 25 formalities surrounding this decision were complied with and I further find that E has not withdrawn it.

63. I note that E added: *"If I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision."* This is not in my view an instruction that could be binding in the light of MCA s. 25(2), referred to above, which provides that the decision will not be valid if the maker has done anything clearly inconsistent with its remaining her fixed decision.
64. I accept that at the time the October 2011 decision was signed, E and her mother had been given reason to believe that E had capacity. E had the benefit of advice from her independent mental health advocate and from a solicitor. This also appears to have been the general medical view, but no formal capacity assessment was undertaken at the time. Moreover, E was again placed under Mental Health Act section on the day the document was signed and on the next day she was received into the care of Professor L for assessment. In his report made on 17 October, Professor L does not specifically deal with the question of capacity, but his general approach can be deduced from the fact that he recommended treatment, despite recording E's opposition very fully.
65. I find on the balance of probabilities that E did not have capacity at the time she signed the advance decision in October 2011. Against such an alerting background, a full, reasoned and contemporaneous assessment evidencing mental capacity to make such a momentous decision would in my view be necessary. No such assessment occurred in E's case and I think it at best doubtful that a thorough investigation at the time would have reached the conclusion that she had capacity.
66. A further question arises as to whether E had, or indeed has, the capacity to make a decision to refuse other forms of treatment such as mechanical ventilation, which might be necessary to sustain her during forcible feeding. Dr Glover's evidence about this somewhat wavered, but in the end he was of the view that she lacks capacity in this respect also.
67. My conclusion is that it is artificial to treat the various forms of intervention involved in forcible feeding individually. They are all central to or supportive of a single purpose. I therefore find that E lacks capacity to accept or refuse treatment in relation to any interventions that are necessary in conjunction with forcible feeding.
68. I further note the submission that since signing the October advance decision, E has done something clearly inconsistent with the advance decision remaining her fixed decision: MCA s.25(2)(c). This refers to isolated statements she has subsequently made:
 - (1) During a psychotherapy session on 12 November 2011, she said that she had made up her mind to live.

- (2) On 15 November, she spoke *“eloquently and articulately of her desire to have a life now that she knows she will not be permitted to die.”*
 - (3) In March 2012, she said to a Dr V that she wanted to travel and study midwifery and nursing.
 - (4) On 8 May, she told a Dr L that she did not want to die, but would like to live a normal life, study and have children.
 - (5) On 16 May, she told Dr D that she is scared, but does not want active treatment.
 - (6) On 24 May, she spoke of saying goodbye, but wanting to choose life and set her own targets.
69. In the light of my prior conclusion that E did not have capacity to make the October advance decision, it is unnecessary to decide whether she has done something clearly inconsistent with it remaining her fixed decision. E’s actual behaviour in refusing food has been entirely consistent with her decision and I would have been reluctant to conclude that her decision was undermined by trusting statements about what are bound to be deeply mixed feelings.
70. For the above reasons, I find that E does not have the mental capacity to make the decision about treatment by forcible feeding and that the court must take the decision that is in her best interests.

E’s best interests

71. The assessment of best interests is governed by s. 4 MCA. The court must consider all the relevant circumstances and take the following steps:
- Consider whether, and if so when, it is likely E will have capacity
 - So far as reasonably practicable, permit and encourage E to participate as fully as possible in the decision
 - Not be motivated by a desire to bring about E’s death
 - Consider, so far as is reasonably ascertainable (a) E's past and present wishes and feelings (and, in particular, any relevant written statement made by her when she had capacity), (b) the beliefs and values that would be likely to influence her decision if she had capacity, and (c) the other factors that she would be likely to consider if she were able to do so.

- Take into account the views of E's parents and carers as to her best interests and her beliefs and values

Recovery of capacity

72. The hope is that, with refeeding, E will reach the point where her weight stabilises at a more normal level (in the order of BMI 17) and leads her to recover the capacity to take decisions for herself. In relation to this, the medical advice is guarded:
- (1) Treatment carries a very high risk to E's physical health and survival, according to Dr B, consultant anaesthetist. She will experience 'refeeding syndrome', which occurs when the body is called upon to undergo a complete metabolic change to deal with the processing of carbohydrates. E is in a fragile condition and the intensity of the medical intervention is such that her chances of surviving or not surviving treatment are no more than equally balanced. There is also an immediate 2-3% mortality risk from the insertion of a PEG line. E is also very vulnerable to physical trauma as a result of her fragile bones.
 - (2) The doctors are cautious about the likelihood of E 'recovering', in the sense of returning to a quality of life that she would regard as being worthwhile. Both Dr Glover and Dr M gave estimates overlapping at a 20% likelihood of recovery.
 - (3) If E survives, the impact of the treatment upon her capacity cannot be known.
 - (4) On the evidence I have heard, it is not likely that she will recover capacity within a year.

Participation in the decision

73. Although E has been unable to participate in the hearing, she has movingly expressed her views to Mr Powell QC, as described below.

Motivation

74. Although one is bound to feel compassion for E's circumstances, a wish to bring about her death plays no part in the analysis of her best interests. No witness, and least of all her parents, spoke in such terms.

E's past wishes and feelings

75. When she has not been acutely ill, E has had the natural aspirations of a highly able and intelligent young woman. Her ambition up to the point when her illness overtook her in her mid-20s was to make a success of her life by using her considerable talents in pursuing a medical career, thereby helping others. She wanted happy relationships and she wanted a family. Over the past six years, these ambitions have dimmed with the progress of her illness.

E's present wishes and feelings.

76. On 21 May 2012, E told Mr Powell QC that she had wanted to live a positive and productive life, but had failed. She recognises that everything that could have been done to help has been tried and that she has endured a lot of pain with very little benefit. She describes her life as "*a pure torment*". All the things she had wanted to do have proved impossible because of her illness. She can't achieve any of her goals and she feels crushed. She feels she is in a situation where she is able to give nothing to the world and the world is able to give nothing to her. She is conscious that she represented a huge burden to her family, who have always been extremely supportive and caring. She feels that her life is pointless. She would have wanted to have a relationship with her sisters' children but because of her condition that is not possible. She has tried to explore every avenue to get over her demons but has failed. She wants to live for the remainder of her life as she chooses, and if necessary to be allowed die with dignity. She understands that she will die without intervention. She does not want to be killed, she just wants to be allowed to act as she wants. It is possible that she might change her mind, but not because somebody forces to do so. She has core beliefs and it will be those beliefs that will determine if she wants to stay alive. She asks the court to respect her wishes.
77. Speaking to Dr Glover on the same day, E pleaded that she does not wish to endure further treatment. She showed him the scars on her abdomen from previous operations and insertions of tubes.

E's beliefs and values

78. The beliefs and values that would be likely to influence E's decision if she had capacity are not easy to articulate. It depends upon an assessment of her true identity. Has she been so ill for so long that her illness would remain part of who she is, even if she had capacity? Or is she still the person she was before anorexia took her in its grip? Looking ahead, will E always see herself as a victim, or can she come to see herself as a survivor? In the end, only E can know the answers to these questions.

79. For present purposes, I find nothing in E's statements to indicate a belief that, if she were well, she would not want efforts to be made to save her. Although the risks of treatment are high and the chances of recovery are low, these are odds that patients and doctors (and E would by now be a doctor but for her illness) willingly accept when considering life-saving medical treatment in other circumstances.

The views of others

E's parents

80. E's parents have lived through her difficulties at every stage. In their statement in these proceedings, they emphasise that E is not just a simple case of anorexia but falls between two stools of mental and physical health which has caused numerous difficulties in providing a cohesive treatment plan. While living in the community, she would often not answer the phone for days at a time and they would come to her flat not knowing whether they would find her alive or dead. They described the degradation in which she had been living. They say:

"After so many years of treatment E still finds it impossible to eat. This is her day-to-day reality. However distorted others might view it to be, it is still her reality.

At the meeting in April 2012, all the clinicians that have been involved in E's care over the last few years met and were all in total agreement that she should proceed down the palliative care pathway. We strongly feel that, five weeks into this pathway, this is an inhumane time to bring this into question, especially for a highly anxious woman. During the last five weeks we have watched our daughter preparing for her death in a very dignified and considered way, with a powerful sense of control over her situation. In this time, she has never faltered from her wish not to be re-fed.

We have always gone along with any treatment proposed by either the mental or physical health teams in the hope that she might show signs of "recovery" from her addictions. After 18 years, we have given up on that hope.

It upsets us greatly to advocate for our daughter's right to die. We love her dearly but feel that our role should now be to fight for her best interests, which, at this time, we strongly feel should be the right to choose her own pathway, free from restraint and fear of enforced re-feed. We feel that she has suffered enough. She stands no hope of achieving the things that she would value in her life and shows no signs of revising these aspirations. We would plead for E to have some control over what would be the last phase of

her life, something she has been denied for many years. For us it is the quality of her life and not the quantity. We want her to be able to die with dignity in safe, warm surroundings with those that love her."

81. E's parents added in their statement that they could only support further intervention if appropriate treatment for both her anorexia and alcoholism is available. This would have to be a different, long-term approach to her complex needs, underpinned by long-term funding for residential treatment and followed by provision of sheltered and supervised accommodation to reintegrate her slowly back into the community. In the past, they have repeatedly been told this funding is not available.
82. The parents modified their views to a limited extent only during the hearing, having heard about the specialist hospital proposal. Their views can be characterised as amounting to grave misgivings about the proposal, but not fierce resistance.

Medical opinions

83. I next refer to the view of two specialists with prior knowledge of E.
84. Professor L is a professor of psychiatry and lead consultant in eating disorders. E was admitted to his hospital for assessment in October 2011. He made these observations at the time:

"E talks about how her "bullet-proof anorexic retreat" is failing her. She needs to find a new foolproof retreat – death. She needs to know she has an exit and has the power to put a stop to things when she wants to. The paradox is how, through her anorexia, she attempts to fortress herself against unwanted invasion and intrusion, and yet in her choice of anorexia, she invites ongoing medical and psychiatric invasion. An example of this is the use of a PEG. The PEG can be seen as a "medical abuse" which links to E's early life experiences. Even her sleep is invaded each night when woken up for nursing procedures.

I see it as an unconscious replay of her childhood sexual abuse – where the scenario is in constant repetition with professionals, as it was with her abuser. The only way she feels she can stop it is through death.

To be invited to make a decision to have a life, a less than perfect life, a compromised life, is absolutely terrifying for her. She would then have to take some responsibility for her fate rather than being able to remain a powerless victim."

85. Professor L describes E's illness as "severe and enduring, though highly manageable and probably treatable".

86. Dr V is also a consultant psychiatrist and lead consultant for eating disorders. She had E in her care for over a year from early 2009 to the middle of 2010. Writing in March 2012, after conversations with E and her medical consultants, she was of the opinion that E had made a competent decision to refuse treatment:

“It does not feel appropriate to fight with her at this point; the fight itself (e.g. physically preventing access to the NG or PEG tube, vomiting, laxatives, trying to keep awake all the time) or the intervention (restraint, sedation) could hasten her death, as well as denying that the dignity that is so important.

Our approach would be to provide all care and support short of force-feeding.”

87. I next record the opinion of Dr Glover, the court-appointed expert. In his report he wrote:

“It is profoundly difficult in a case as complicated as this to disentangle a patient’s best interest.

One cannot help be influenced by the sincerely held view of her two loving parents.

However, my long and detailed analysis of her care record indicates that E has remained at a BMI of less than 15 for at least six years.

It is widely understood within Eating Disorder Psychiatry that many patients will not recover from the effects of malnutrition unless they have had their BMI increased to 17 or above.

The only time that E’s BMI was “forcibly” restored to normal was during her treatment... at the age of 15. It is of note that she went on to complete her A levels and gain a place at medical school in the ensuing years.

Although E has been treated at [three named clinics], at no time during these placements has the treatment plan insisted upon consistent weight gain up to a BMI of over 17.

Indeed, it is notable that E’s improvement is so marked as her BMI increases towards 15 that she is allowed a greater say in her treatment, with the effect that she has repeatedly, thereafter, defaulted from further weight gain and re-entered a cycle of food avoidance and weight loss.

Treatment regimes enforcing weight gain appear, to the outsider, somewhat barbaric. The categorical refusal to ingest calories can only be met with

forcible feeding either under physical or chemical restraint. This is harrowing for any patient, but particularly for one who was subjected to extensive childhood sexual abuse.

However, one cannot be reassured that a treatment for Anorexia has been “ineffective” unless and until a period of enforced weight restoration has been secured. E’s history shows abundant evidence of partial cooperation with re-feeding, a dramatic improvement in mental state, an increased responsibility for the management of her own diet, and her inability to continue with a programme of weight restoration.

Were this a simple case of Anorexia Nervosa with no co-morbidity I would have no hesitation whatsoever in recommending that she receive nutrition in her best interests. E, unfortunately, also suffers from an Alcohol Dependence Syndrome, and Emotionally Unstable Personality Disorder (borderline subtype). The interplay between these three diagnoses is extremely complex. Professor L, in his report, gives a sophisticated argument as to why E is engaging in this repeated pattern of behaviour, the result of which is to lead to repeated cycles of “abuse”.

The clinical situation is now extraordinarily complex. E is profoundly malnourished, and perhaps on the brink of death. Furthermore, she is receiving significant quantities of opiate medication and is undoubtedly dependent on this medication. She and her family are psychologically adjusted to the prospect of her imminent death.

The treatment of E as a person rather than a physiological preparation is likely to be torrid. As well as withdrawing from opiate medication she will require forcible re-feeding and would require transfer to a specialist eating disorder unit for that treatment.

Although this decision is finely balanced, I believe that it is in E’s best interests to receive nutrition and hydration. I form this opinion with reference to three particular facts:

- E’s BMI has not been raised to 17 or above for over seven years. Without this having been achieved it would be unsafe to deem the withholding of nutrition to be in her best interests.*
- E shows a significant improvement in her mental state as her BMI is increased to 14.5/15.*
- Following her treatment at the age of 15, when her BMI was restored to normal, there followed a period of relative stability and high academic achievement.”*

88. Giving evidence, Dr Glover said that, provided there was a near-optimal treating team and environment, it should be possible to raise E's BMI to 17 but that it would require forcible feeding under physical or chemical restraint for not less than a year. This would consist of the introduction of 300-500 calories three times a day by nasogastric tube or by gastrostomy, carried out under physical restraint or with a level of sedation that would overpower the ability to resist. As an alternative, E could be tube fed overnight using a continuous pump. He noted that in the past E had repeatedly and successfully resisted tube feeding.
89. In Dr Glover's view, E finds it intolerable to confront her past experiences. By lowering her weight and by abusing alcohol, she achieves emotional numbness. Force-feeding is the very last thing that an anorexic wants and with E's specific history, she experiences it as a re-enactment of abuse.
90. As to prognosis, Dr Glover is of this opinion:

"In terms of E's Anorexia Nervosa, I would estimate that were she to be re-fed to a BMI of 17 or above and her weight maintained there through the use of the Mental Health Act and/or Community Treatment Orders, she would have, perhaps, a 20-30% chance of full recovery. Although I am not an expert in the field of substance misuse I am well aware that successful treatment for alcohol dependence can occur after many years of dependence and although E's history of persistent alcohol dependence is unfavourable in terms of prognosis, it should be remembered that this pattern of misuse has occurred on a background of persistent and profound malnutrition.

In terms of her personality disorder, should this indeed be the correct diagnosis, these patterns of behaviour can persist for many years despite long periods of psychotherapy. Again, the pattern of behaviour which has led to the formulation of this diagnosis has occurred on the background of persistent and profound malnutrition. Should this pattern of behaviour persist following restoration of weight, there are numerous psychotherapy approaches, including residential, which have proven to be effective in terms of managing this condition, in particular Dialectical Behaviour Therapy (DBT).

E's opiate dependence has been developing over a number of years. She has now reached a point where she is clearly opiate dependent and currently on a clinically supervised maintenance regime. This condition, again, falls outside my sphere of expertise. However, I am well aware of detoxification programmes which could be employed in E's case involving the controlled withdrawal of her opiate medication and replacement with other forms of analgesia. Subsequently, addiction treatment programmes aimed at

enhancing E's motivation to remain abstinent from harmful substances could be employed and are well recognised as having a significant level of success."

91. As to this last point, Dr Glover noted in his oral evidence that as a result of the end of life pathway, E is now addicted to diamorphine and has not had her physical condition monitored or treated for some time.
92. He emphasised that, while BMI is a useful measure, quality of life is what one is looking for. Her quality of life has of course been extremely poor for the last six or seven years. Because she has not had her BMI restored to 17 or above, she has not had a chance to recover and to maintain recovery. He considers that if treatment was successful she might be happy, eat normally, work and enjoy pastimes.
93. Dr Glover identified that a bed is available under Dr M at the specialist hospital, and E's health authority is willing to pay the costs, which might be in the order of £200,000 – £300,000 annually, if this course is regarded as being best for her.
94. Dr Glover says that without embarking upon this course one could not be certain that it is not in E's best interests to receive artificial nutrition and hydration. Asked if such a course was worthwhile, he said that we have not proven that it is not. In his view the decision turns upon the fact that every possible solution has not yet been tried and shown to fail. For him to advise against force-feeding, the prospects of success would have to be so slight as to be negligible. He writes: *"Although to an outsider, treatment periods of 18 months in one [named unit], three months in another [named unit], and a further assessment by Professor L may seem adequate if not excessive, in a case as severe as E's, my opinion is that it has been inadequate. Patients such as E often require years of highly specialist treatment at nationally recognised centres such as [the specialist hospital]."*
95. Asked about his initial view that E should not be re-fed, he replied:

"That was naive. The reason was, I anticipated seeing in her notes a pattern of engagement with specialist eating disorder services over many years. I would expect a patient like her to be in a specialised unit for 5 of the last 7 years. The difference is that she has not really accessed meaningful treatment in a highly specialist unit like [the specialist hospital]. She hasn't had her weight restored to BMI 17. Without that I realised I could not be certain at all that it was in her best interests not to receive ANH..."
96. Dr Glover is of the opinion that the complexity, chronicity, and severity of E's condition has totally exhausted local resources, whose efforts over many years he described as nothing short of heroic.

97. He acknowledges that E is likely to resist treatment with everything she has, and that any further chemical and physical insults will lead her closer to death. He drew attention to refeeding syndrome, as described above. However, the risks associated with refeeding are in his view better than death.
98. Dr Glover described it as *"a gargantuan task to take her from where she is now to where we want to go"*. The first steps would be fraught with difficulty. E cannot be treated at her current hospital, which lacks the necessary facilities, and it would have to be established whether she was fit to be moved to somewhere where she could be treated. Her condition is so weak that she might require mechanical ventilation to prevent her from dying in the course of treatment. In answer to a question from the parents, he said that even if E's body gave out, he would think it right to resuscitate her.
99. He felt that E's statements were ambivalent. *"E does not want to eat. I don't think she wants to die."* His instinct is that she is detainable for treatment under the Mental Health Act.
100. In conclusion, he said that it is a very difficult decision and that *"E's case is as hard as it gets."*
101. Dr C, E's consultant gastroenterologist and acute physician, has been involved in E's treatment since 2009 and knows her well. He describes her as *"a highly intelligent and articulate lady who I have enjoyed talking to over the years that I have cared for her. In my opinion she can at times clearly delineate between her disease and her sustained wishes to be offered dignity at the end of her life. I note that at no point has Dr. Glover had the opportunity to talk to E when she is well."*
102. Dr C saw E on 27 May. She was drowsy and, although frail and painfully malnourished, ambulatory and mostly coherent. She said that she was excluded from the proceedings and felt that she has something to say to the court, but later on called him to say that this thought provoked significant anxiety.
103. Dr C refers to a report known as MARSIPAN (Management of Really Sick Patients with Anorexia Nervosa) published by the Royal College of Psychiatrists, to the Royal College of Physicians report in October 2010, and to the NICE National Clinical Practice Guideline Number CG9: Eating Disorders.
104. He says that E's wishes for palliation have been consistent. She had even been willing to raise her BMI in order to make an advance decision.

105. He has discussed E with Dr M at the specialist hospital.
106. Dr C refers to the chance of death from anorexia. He says that within the NICE guidance the overall chance of dying from the condition is 0-21%, the majority of the deaths being from suicide or from physical ailments related to anorexia. Dr C speculates that E's risk of mortality might be at the upper limit of this range, because of the severity and complicating features of her condition.

107. As to further treatment, Dr C writes:

"When the Court is considering the question of best interests I would draw attention to the fact that I have been repeatedly told by each new expert that this is not a hopeless situation and to refeed E. Each time E has gone through the distress this causes her to be found back in the same situation. With the longevity and severity of her disease I am afraid I am sceptical as to the ability of any specialist to cure E.

E has a difficult to treat combination of problems including personality disorder, dependence on drugs and alcohol as well as anorexia. My problem is not whether I can or will refeed E again, but how many times do I take E through the trauma and at what point should it be decided that refeeding is futile?

Refeeding E is not easy and contains many risks. I have re-fed her on multiple occasions. I would point out the near certainty that over and above psychological distress that would be caused there are significant life threatening risks to undertaking refeeding.

Previously on re-feeding E, she has suffered re-feeding syndrome which is a condition that is induced by starting feeding and has a risk of killing E. It is likely that E will suffer more significant refeeding syndrome on this occasion.

In her current state of extremely frailty E may die irrespective of the court deliberations. She would reach many of the MARSIPAN criteria and even ambulance transport to a local intensive care unit would carry significant physical risk. The physical risk is that of heart rhythm problems, heart failure, and malnutrition related complications such as brain or nerve damage. Refeeding E takes a prolonged period of time with significant mental distress to her. She has told me it feels like reliving the abuse she suffered as a child approximately four times every hour."

108. Dr C describes E as incredibly able, capable, and determined. She is stubborn and will excel at anything she does. His personal view is that there is a futility in repeated cycles of treatment, but he sees it as a profoundly difficult

decision and would support either outcome. He gave valuable evidence about the treatment procedures that are available and confirmed that if E's heart failed, he would attempt brief defibrillation but would not perform prolonged CPR.

109. Dr D has been E's consultant psychiatrist during the course of her admissions during the past 6 years. His understanding is that all treatments have been tried and have not done any good. He considers that she has intermittent capacity. He said: *"She has come to the state where she is clearly telling us:– 'Please leave me alone' – a statement for which I think she has capacity"*.
110. Dr D did not consider that E had capacity to make an advance decision in July 2011, but that she did in October 2011, although he had not formally assessed her at the time.
111. Dr D said that he would be willing abide by the court's decision and would participate in placing E under a Mental Health Act section to ensure that treatment was carried out.
112. Finally, Dr M of the specialist hospital gave brief evidence. She is a consultant psychiatrist and specialist in eating disorders. Her hospital has a 20 bed inpatient unit occupied by patients with very severe eating disorders, and in some cases comorbidity of the kind E experiences. The staff has the full range of expertise and is highly experienced in refeeding patients with very low weights. She considered that they could offer a programme with a degree of persistence and unity of purpose that E has not so far experienced.
113. Dr M described E's prognosis for recovery as quite poor, in the order of 10-20%. She noted, however, that she had not had much specialist treatment since adolescence. It was unlikely that E would resist refeeding once the process started. She would probably need to remain at the hospital for 1-2 years and might be eligible for a specialised community placement after that.

Best interests: the factors

114. The advantages and disadvantages of each course of action must be balanced out.
115. The factors that speak in favour of continued palliative care are these:
 - It reflects E's wishes
 - It respects E's personal autonomy
 - It spares E the risks associated with treatment
 - It avoids the harrowing aspects of treatment
 - It allows E to die with dignity and close to home

- Treatment has limited prospects of success
- E's parents and clinicians are at best sceptical about it

116. The factors that speak in favour of treatment by forcible feeding are these:

- Without treatment, E will die
- Without treatment, E will lose the chance to recover and lead a relatively normal life
- There is medical opinion that E is treatable with some prospect of success
- The longer E lives, the greater the opportunity for her to benefit from treatment and to revise her views about her future

117. In balancing these factors, I do not gain direct assistance from the facts of reported welfare decisions. In contrast to the case of W v M (above), where the patient was in a stable, minimally conscious state, E is in an inexorably deteriorating, highly conscious state. In contrast to the cases of Re W (A Minor)(Medical Treatment: Court's Jurisdiction) CA [1993] Fam 64 and Re C (Detention: Medical Treatment) [1997] 2 FLR 180, E is not a teenager but an adult with an entrenched history of acute difficulties. In further contrast to many medical treatment cases, the psychological impact of the proposed treatment upon E is of a different order to many other cases. The treatment would not consist of a single operation or procedure, but a wholesale overwhelming of her autonomy for a long period whose exact length could only be measured in hindsight once it was known whether treatment had succeeded or failed. Further, because of the complexity of her condition, the success of treatment is particularly uncertain. Perhaps finally, in distinction to more recognised situations, there is the fact that E and her family and her medical team had already firmly embarked on the course of palliative care and had psychologically adjusted to the prospect of imminent death.

118. 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.

The right to life

119. All human life is of value and our law contains the strong presumption that all steps will be taken to preserve it, unless the circumstances are exceptional. This principle is reflected in Article 2 ECHR, which provides that everyone's life shall be protected by law. It is the most fundamental of the Convention rights.

120. However, the principle is not absolute and may yield to other considerations: Airedale NHS Trust v Bland [1993] AC 789.

121. Likewise, the MCA might have given absolute priority to the preservation of life, but it does not. The approach taken by the Act is accurately reflected in the MCA Code of Practice at 5.31:

“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.”

122. E's life is precious, whatever her own view of it now is. She is still a young woman, with the possibility of years of life before her. The prospects of her making a reasonable recovery are highly uncertain, but it cannot be said that treatment efforts are doomed to fail or that treatment would inevitably be futile.
123. As to the quality of E's life if she were treated, it is possible, but not probable that she could achieve a state of being that would be acceptable to her. It is more likely that the underlying difficulties would remain and that her life would continue at best to be a struggle. It would in part depend upon the quality of support and professional services that would be available and whether they would be different to what has been available in the past.

Respect for personal independence

124. The ability to lead one's life as one chooses is the cornerstone of individual liberty. Article 8 ECHR guarantees the right to respect for a person's private life. This right belongs to “everyone” and the fact that a person lacks mental capacity does not deprive them of its protection.
125. The treatment that is proposed for E amounts to a very severe interference with her private life and personal autonomy. It could only be justified on the basis that it was necessary, in accordance with the law and proportionate to a legitimate aim, namely the preservation of life.
126. Likewise, forcible feeding would be an assault upon E and a violation of her rights under Article 3 ECHR, which prohibits inhuman or degrading treatment, unless it was shown to be in her best interests on the basis of therapeutic necessity that has been convincingly shown to exist: Herczegfalvy v Austria [1993] 15 EHRR 437.
127. E's wishes and feelings, as described above and written down by her in an attempt to control her treatment, are clear. They are not the slightest bit less real or felt merely because she does not have decision-making capacity. I agree with the submission of Mr Bowen QC and Mr Broach that particular

respect is due to the wishes and feelings of someone who, although lacking capacity, is as fully and articulately engaged as E.

128. E's self-image has for many years been as a person with an eating disorder. As her parents say of her way of life: "*However distorted others might view it to be, it is still her reality*". This has become extremely important to her. She wanted to excel in a conventional way but has instead sadly become a high-achiever of a very different kind. Professor L records that she seemed to take pride in being "*the most treatment-resistant patient they had ever had*".

Decision on best interests

129. In E's situation, any decision is a heavy one. The balancing exercise is not mechanistic but intuitive and there are weighty factors on each side of the scales.
130. On one side, I have been struck by the fact that the people who know E best do not favour further treatment. They think that she has had enough and believe that her wishes should be respected. They believe that she should be allowed a dignified death. I respectfully acknowledge the impossible position of E's parents, and the dignified way in which they have conducted themselves. Like the Official Solicitor's representative, Mr Powell QC, I was struck by their caring, thoughtful and insightful approach. I also pay tribute to the quality of care and commitment shown by E's medical team.
131. I have also reflected on what is involved in the course of treatment. It does not merely entail bodily intrusion of the most intimate kind, but the overbearing of E's will in a way that she experiences as abusive.
132. E's views are entitled to high respect. She is not a child or a very young adult, but an intelligent and articulate woman, and the weight to be given to her view of her life is correspondingly greater.
133. Regard must also be had to the fact that this application was only brought after E and her family and carers had embarked a long way down the course of palliative treatment. The state is now seeking to intervene very late in the day and a return to compulsion will be excruciating for them.
134. No do I accept the proposition that one can only be certain about E's best interests if every possible solution has been tried and shown to fail. If taken too far, the argument that everything that can be done must be done carries the risk of discrimination against incapacitated persons by depriving them of options that are available to the capacitous, such as the patient in [Ms B v An NHS Hospital Trust \[2002\] EWHC 429 \(Fam\)](#). (It will be recalled that Ms B was a young woman who was paralysed by sudden catastrophic illness and was

dependent on mechanical ventilation and total nursing care. She chose to refuse continued life support despite retaining full mental abilities and having a substantial expectation of life. Her decision was upheld by the court, and she died.)

135. I acknowledge the significant risks involved in treatment, not excepting a risk to life. I acknowledge the modest prospects of success and the wholesale and prolonged invasion of E's privacy and self-determination that is proposed. I acknowledge the high chance that, even if short-term progress can be made, long-term difficulties will remain. I accept that E may recover capacity only to make a valid advance decision. I accept that a resumption of treatment deprives E of an imminent and relatively peaceful death.
136. These are all weighty factors.
137. Against them, I place E's life in the other scale. We only live once – we are born once and we die once – and the difference between life and death is the biggest difference we know. E is a special person, whose life is of value. She does not see it that way now, but she may in future.
138. I would not overrule her wishes if further treatment was futile, but it is not. Although extremely burdensome to E, there is a possibility that it will succeed. Services and funding will now be provided that were not available before, and it would not be right to turn down the final chance of helping this very vulnerable young woman. I accept that the nature of the treatment is different to anything E has previously been offered, and I am reassured, rather than discouraged, by the realistic outlook of Dr M.
139. I am also influenced by the fact that those who know E best are not in outright opposition to treatment taking place, however sceptical they justifiably feel.
140. The competing factors are, in my judgment, almost exactly in equilibrium, but having considered them as carefully as I am able, I find that the balance tips slowly but unmistakably in the direction of life-preserving treatment. In the end, the presumption in favour of the preservation of life is not displaced.
141. I declare that E lacks capacity to make decisions about life-sustaining treatment, and that it is lawful and in her best interests for her to be fed, forcibly if necessary. I find that the resulting interference with E's rights under Articles 8 and 3 is proportionate and necessary in order to protect her right to life under Article 2.

142. I confirm that the treatment plan that has been under discussion is illustrative, and that the course of treatment must be a matter for the professional judgment of the medical team that will be looking after her.
143. I record that the state, having instigated this plan of action for E in the way that it has, is now honour-bound to see it through by the provision of resources in the short, medium and long term. Had the authorities not made that commitment, I would not have reached the conclusion that I have.