This Judgement consists of 71 paragraphs. Pursuant to CPR 39A para 6.1 no official shorthand note shall be taken and copies of this version as handed down may be treated as authentic.

N.B. AN ORDER IS IN FORCE PREVENTING THE IDENTIFICATION OF THE SUBJECT OF THESE PROCEEDINGS AND OTHERS ASSOCIATED WITH HER OR HER TREATMENT

Neutral Citation Number: [2012] EWHC 2741 (COP)

Case No: COP 12191473

IN THE HIGH COURT OF JUSTICE
COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 30/08/2012

Before :

MRS. JUSTICE ELEANOR KING

- -

Between :

The NHS Trust	**Applicant**
- and -	
'L'	**1st Respondent**
By her litigation Friend the Official Solicitor)	
- and -	
The Psychiatric NHS Trust	**2nd Respondent**
- and -	
Mrs 'L'	**3rd Respondent**
- and -	
Mr 'L'	**4th Respondent**

- -
- -

Bridget Dolan (instructed by DAC Beachcroft) for the **Applicant**
Jeremy Hyam (instructed by The Official Solicitor) for the **1st Respondent**
Parishil Patel (instructed by Hempsons) for the **2nd Respondent**
Mrs. 'L' appeared in person as **the 3rd Respondent**
Mr. 'L' appeared in person as **the 4th Respondent**

Hearing dates: 24th August 2012

- -

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

MRS. JUSTICE ELEANOR KING

Mrs. Justice Eleanor King :

1. The Applicant NHS Trust seeks a declaration of the utmost gravity namely that it is not in the best interests of a young woman, Ms L, to be the subject of forcible feeding or medical treatment notwithstanding that in the absence of such nutrition and treatment she will inevitably die.

2. Ms L, who is now 29, suffers from anorexia nervosa of a severity and unremitting nature which is extraordinarily rare in the United Kingdom. Ms L first showed symptoms of anorexia nervosa when she was only 12, her first period as an inpatient taking place when she was 14. Despite treatment in virtually every centre of excellence in the country she has, for the last 16 years spent 90% of her young life as an inpatient in various units, often compulsorily detained under the provisions of the Mental Health Act.

3. Since March 2012 Ms L has been treated in a University Hospital run by the NHS Trust. Dr Glover the independent expert in eating disorders instructed to report in the case has, expressed his admiration for the treatment Ms L has received over the many years; the team at the University Hospital where she is currently treated, have he told the court, been extremely innovative in the treatment options and the strategies they have employed including taking a positive approach to risk taking, with a determined focus on improvement in the quality of Ms L's life. Tragically for Ms L it has been to no avail, Ms L continues to lose weight, she has end stage organ damage with a very poor prognosis. She now weighs only about 3 stone.

4. It is hard to imagine a more dedicated family than that of Ms L. Her mother Mrs L has, perhaps inevitably, borne the brunt Ms L's illness but that is not in

anyway to detract from the love and support she has had also from her father Mr L. The family's life has of necessity centred round the pernicious and often misunderstood illness which enveloped their daughter before she even entered adolescence; for 16 years they have visited hospitals all over the country virtually daily as they tried to support their daughter to get well. One suspects that only those who have had to cope with the tragedy of severe and unremitting mental illness within their family can really understand what they have been through.

5. Ms L also has a younger sister Ms KL. Throughout Ms KL's sentient life her sister has been ill and her parents living under the constant anxiety and strain attendant upon that illness. Ms KL attended court with her parents and, at my encouragement she, (as well as her parents), asked questions of the experts. Ms KL showed no hint of resentment or bitterness at the impact her sister's illness had had on her own life but only a desire to understand the advice given by the experts in order to contribute towards a decision as to what is now in her sister's best interests.

6. No one in court could do other than have unreserved admiration for the L family, no family could have done more than they have done to support Ms L; it is a measure of the severity of her illness that despite that support and the exceptional medical treatment she has received, Ms L's prospects of recovery are now negligible.

7. Reversing Ms L's malnourished state by forcibly refeeding her provides the only faint possibility of reversing her weight loss and preserving her life. That being the case the issues now before the court are:

i) to determine whether or not the decision to subject Ms L to forcible refeeding should now be taken out of her hands on the basis that she lacks the necessary capacity to make that decision and

ii) if so, is it or is it not in Ms L's best interests to be force fed.

8. The hearing, which took place last week, was conducted somewhat unconventionally from a procedural point of view. The NHS Trust and NHS Psychiatric Trust were represented by Counsel as was Ms L through the Official Solicitor. The family did not have legal representation.

9. It became clear at a very early stage in the proceedings that the draft declaration which had been prepared by Miss Dolan on behalf of the NHS Trust was a work in progress and that with the considerable assistance of Dr Glover, and Dr B (Ms L's treating gastroenterologist); the parties were edging towards an agreed draft to put before the court. Accordingly I heard oral evidence from Dr Glover and Dr B but rose from time to time to give all the parties but particularly the family time to discuss issues which they found difficult and to work on a form of words to put before the court.

10. I am grateful to both doctors who not only gave the court lucid, measured and invaluable advice and guidance but also offered the family incalculable support, explaining and clarifying their evidence and also relaying to the court anxieties which had been expressed by Mrs L to them but which she had difficulty in putting into words in court.

11. Dr. Glover, through his written and oral evidence gave the court real insight and understanding into the warped perception a sufferer of anorexia nervosa has in all matters which relate to food. With the benefit of his evidence all present were far better able to comprehend how this bright intelligent and much loved young woman comes to be teetering on the brink of death.

12. The family expressed their gratitude to all the treating team and left court knowing that their views and unmatched understanding of their daughter will be at the centre of decisions in relation to her treatment which will now focus on minimising Ms L's distress and maintaining her dignity.

The Law

13. People with capacity are entitled to make their own decisions, including about what they will and will not eat, even if their decision results in their death. The court, 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.

14. Where the court finds that a person lacks capacity then it has a duty to make a decision that is in that person's best interests.

15. The first question therefore is whether Ms L has capacity to consent to being forcibly fed. The second, which can only arise if she does not, is what decision is in her best interests.

The Mental Capacity Act 2005

16. 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) …

The Human Rights Act 1998

17. 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 such a way which is compatible with the European Convention on the Protections of Human Rights and Fundamental Freedoms 1950. For the purposes of today the relevant rights under the Convention are those contained in Articles 2 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.

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.

18. Five years before the enactment of the HRA 1998 Lord Goff set out in *Airedale NHS Trust v Bland (H.L) [1993] AC 789* what has become the seminal judicial expression in relation to the potential tension and seeming irresolvable conflict as between the sanctity of life and the withholding of medical treatment.

> "….Here, the fundamental principle is the principle of the sanctity of human life- a principle long recognised not only in our own society but also in most, if not all, civilised societies throughout the modern world, as is indeed evidenced by its recognition both in article 2 of the European Convention for the Protection of Human Rights and Freedoms (1953) and in Article 6 of the International Covenant of Civil and Political Rights 1966
>
> But this principle, fundamental though it is is not absolute. Indeed there are circumstances in which it is lawful to take another man's life for example by a lawful act of self defence, or (in the days when capital punishment was acceptable in our society) by lawful execution. We are not however concerned with cases such as these. We are concerned with circumstances in which it may be lawful to withhold from a patient medical treatment or care by means of which his life may be prolonged. But here too there is no absolute rule that the patient's life must be prolonged by such treatment or care, if available, regardless of the circumstances."

19. Artificial nutrition of the type which would be necessary in Ms L's case is a form of medical treatment for these purposes: MCA Code of Practice 9.26

20. Examples of cases where life-sustaining treatment has either been withheld or withdrawn where the patient in question was not in a Permanent Vegetative State (PVS) were highlighted by Baker J in his recent review of the law on the subject in *W v M & Ors [2012]1WLR 1653*

Ms L's Illness

21. At the age of 14 Ms L was admitted to an inpatient child and adolescent facility with experience in the management of anorexia nervosa. Ms L was an inpatient for 12 months and although she gained some weight even then she was unable to achieve her target weight of 39kg (6st 2lb). Upon discharge her weight began to drop immediately. This unpromising start to her treatment became the pattern for the next 16 years. Ms L has been unable to sustain any

psychological or physical improvement without the intense support offered by inpatient treatment and, on the rare occasions when attempts have been made to discharge her home, her weight has dropped dramatically and her physical condition deteriorated dangerously.

22. Dr Glover sets out in his report the many and varied approaches which have been attempted both physical and psychological, all to no avail. Despite L understanding intellectually the gravity of her situation she has resisted the efforts of the clinical staff to ameliorate her condition and on occasion been physically and verbally abusive. She has had numerous hospital admissions for various associated medical issues including pneumonia and tuberculosis.

23. In January 2012 Ms L's current detention under Section 3 of the Mental Health Act was rescinded after the eating disorder team concluded that all treatments had been exhausted and compulsory treatment had been shown only to reinforce her eating disorder and increase her disability. In early 2012 Ms L had hoped to move from hospital to a nursing home but, for reasons no one has been able to fathom, (but seem likely to relate to the nursing home having second thoughts as to whether they were willing to accept the responsibility of looking after Ms L), the nursing home in question withdrew their offer of a bed. Ms L was devastated and reacted by reducing her food intake; this resulted in her becoming profoundly and dangerously hypoglycaemic. Ms L was as a consequence transferred to hospital by ambulance in March 2012 for emergency medical treatment.

24. On her admission to hospital Ms L was in a very serious condition. It was anticipated that she would die over that first week end although Ms L, not for

the first time, once again defied the odds and survived; she remained and remains critically ill. A decision was made on 19 March 2012 (and accepted by the family) that in the event that Ms L suffered a cardiac arrest she would not be resuscitated. (a DNR CPR decision). That direction remains in place.

25. Ms L has remained on the gastroenterology ward since March where exhaustive attempts have been made to engage Ms L in a re-feeding programme.

26. Initially on admission on 19 March Ms L tolerated a gradual increase in naso-gastric feed. Unable however to face the increase in calories, she bit through the tube after a number of days. This she did by curling up the tube from the back of her throat with her tongue and swallowing the distal end; a highly dangerous thing to do and impossible for nursing staff to spot as the length of tube external to her nose, (which is measured), remains unchanged. Ms L has had previous admissions to intensive care for aspiration pneumonia, and given the risk of aspiration should Ms L tamper with the naso-gastric tube again, the naso-gastric feed was stopped on 30 March 2012.

27. From April 2012 the unit managed Ms L's illness by an oral diet; an oral diet in this context is not one which a person not suffering from anorexia nervosa would recognise. The nutrients come in liquid form in sealed foil containers. Mrs L described to the Official Solicitor's representative how Ms L refused to use a straw. She would cut a small hole in the foil lid with the top of a biro and then lift it to her mouth, and suck out the contents whilst distracting herself from the knowledge that she was taking in calories by flicking through magazines with her left hand. Mrs L said that this was the hardest way Ms L

could devise to drink the liquid; it caused her pain in sucking, it required the most effort and therefore, in her mind, used up the maximum possible number of calories in consuming the drink. On 20th July as part of her overall debilitation, Ms L's left arm became swollen with fluid and hard to use, this meant that she was unable to turn the pages of her magazine whilst she drank the oral feed. Since that time she has refused all food by mouth and was therefore maintained for next ten days only by dextrose with no balanced feed.

28. By mid July Ms L's condition was, inevitably, further deteriorating:

i) Ms L has lost approximately 3.45kg (about half a stone) since March. She currently weighs about three stone with a body mass index of 7.7 (currently around 8.3 but this I am satisfied is artificially high due to faecal packing)

ii) She has impaired liver function.

iii) She has no subcutaneous fat at all and, despite expert and intensive management of her skin, she has serious pressure sores which cause her significant pain (described by her to be at level 10 if (on a scale of 1 – 10), 10 is the worst pain), until her recent bout of pneumonia this was treated with morphine and will be so treated again.

iv) She has evidence of end stage organ damage and it is likely that she has muscle breakdown and renal damage.

v) Her bone marrow is completely compromised so that she has no resistance to infection and she has MRSA and has to be nursed in isolation.

29. As a result of her deteriorating condition, a series of clinical meetings were held in mid July; Mrs L was present at two and Mr L at one. I have no doubt that Ms L's parents were very shocked and distressed by what they heard at those meetings. Future treatment options were considered and also the fact that, although it was felt she lacked capacity to make such a directive, Ms L was saying that she wanted to make an advance directive so that she could refuse treatment for her hypoglycaemia.

30. Ms L's condition had deteriorated further since her refusal to take oral feeds, and a decision was made to come urgently to the Court of Protection for a declaration as to Ms L's capacity and guidance as to what was in her best interests in relation to her future her treatment and management.

31. At about this time Ms L had a discussion with her mother, she said she did not want to die and still hoped to become strong enough to move to a nursing home. On 27 July 2012 Ms L recorded her personal wishes in writing, in it she says that she would like to move to a nursing home and that if funding was in place she felt that she would then have the motivation to move forward.

She said:

I feel the best option for me to successfully do this would be to get stronger on the NG tube

Currently I feel an oral diet would be too much for me and also create too much anxiety for me

The NG tube could be short term to get me back on my feet and in a stronger position to move forward.

Thank you for taking time to read my wishes. I appreciate your acknowledging my wishes/thoughts.

32. On 1 August feeding by NG tube was recommenced.

33. On 3 August the NHS Trust appeared before Mr Justice Ryder with the Official Solicitor present to ensure that Ms L's interests were protected. Mr and Mr L decided not to attend but were kept informed. In simple terms Ryder J, as a holding position, until an independent Intensivist Dr Danbury and an independent Psychiatrist Dr Glover could report, made three declarations namely:

    i) That the court has reason to believe that Ms L lacks capacity to litigate or to make decision in relation to serious medical treatment

    ii) The clinicians would be permitted not to "force-feed" Ms L

    iii) The clinicians would be able to administer dextrose in order to save her life, if necessary using the minimal degree of force practical and necessary to achieve the same.

The Present Position

34. Dr Danbury and Dr Glover have each reported remarkably quickly. Dr Danbury's report was a so called 'paper' report and did not necessitate him seeing Ms L or the family. Dr Glover however has seen and spoken not only to Ms L and her parents but the clinicians (including the nursing team) who were looking after her.

35. Dr Glover is a Consultant Psychiatrist specialising in eating disorders in full time practice with a particular expertise in the management of severe anorexia nervosa. Dr Glover is also a fellow of the Royal College of Anaesthetists

which gives him an additional, invaluable, understanding of the physical and metabolic consequences of severe malnutrition.

36. The two treating consultants Dr A (Consultant psychiatrist) and Dr B (gastroenterologist) and Drs C & D are all in agreement as to Ms L's capacity, her current state of health and her prognosis. I heard oral evidence from Dr B and Dr Glover; both were impressive witnesses whose absolute objective was to maintain Ms L's dignity and to alleviate her pain and distress in the period between now and what each regards as her inevitable death.

37. Ms L is presently accepting 25mls per hour of nutrients through a . This provides her with only 580 calories a day. This is insufficient even to maintain the little weight she retains. Ms L will not permit an increase to even 26ml an hour, a tiny amount, which she says cannot be justified as she is largely confined to bed and therefore "inactive." At least 30ml per hour is necessary for Ms L to put on weight. Mrs L said that Ms L watches the food coming through the tube and it is "torture" for her. A choice of word used by a number of clinicians when describing Ms L's pathological fear of food and weight gain.

38. Although Mrs L has not bitten through the tube since the beginning of August, her co-operation is precarious; she refuses to have the tube on top of the covers where it is visible to nursing staff. On a number of occasions the tube has blocked, which is most unusual, and is felt to have been caused by her nipping the tube to slow the flow and reduce her intake to below 25 ml an hour. Ms L struggles with any change to her routine and when Dr Glover visited her in hospital before preparing his report, she unscrewed the

connection between the feed bag and the naso-gastric tube. Ms L has found out the codes to the feeding equipment and monitors the quantities of nutrients she is fed.

39. Recently, when Ms L had a hypoglycaemic attack, she refused oral dextrogel and it therefore had to be given intravenously: when she recovered consciousness she saw that she was being given 250mls an hour of the dextrose (a quantity necessary to prevent her falling into a coma from which she would die). Ms L became extremely agitated and angry saying that she could not have two lots of nutrients at the same time (the dextrose and the naso-gastric feed) and pulled out her NG tube despite knowing how unpleasant she finds the procedure of replacing the tube.

40. As Ms L's health has deteriorated she has become subject to recurrent and spontaneous hypoglycaemic episodes. These are, on the one hand, very serious as left untreated the patient slips into a coma and dies but on the other hand simply and effectively treated by a dextrose gel administered orally, through an IV line or, failing all else by a central line.

41. These episodes are extremely distressing for Ms L. One of the features of her illness is that she suffers from severe Obsessive Compulsive Disorder (OCD) as a result she becomes extraordinarily agitated in the event that any gel gets on her skin, hair, clothing or even (her mother tells me) her bedside table. The nature of the treatment is that it has to be given urgently to prevent Ms L slipping into a coma and so, almost inevitably, some gel gets on Ms L and on her belongings. Ms L therefore prefers to be given the dextrose through an IV line, this in itself is problematic as it is harder and harder for even the most

expert clinicians to find a vein in her emaciated body through which they can administer the dextrose. At the present time Ms L is receiving antibiotics for pneumonia and so that access can be used. Insertion of a central line is also problematic being very invasive.

42. It has been noted that whilst the 25ml per hour of nutrient that Ms L is currently willing to countenance is insufficient to maintain her weight, it is having the not inconsiderable benefit of dramatically reducing the number of hypoglycaemic episodes from which Ms L suffers. Given the great distress these attacks cause and the problems in treating them outlined above, all involved in her care support the continued provision of nutrients by NG tube for so long as Ms L is willing to receive it, if only as part of a palliative programme to reduce the incidence of hypoglycaemic attacks.

43. Dr Danbury, a consultant Intensivist and Anaesthetist was asked on behalf of the Trusts and the Official Solicitor, to assess Ms L's condition and prognosis, and to consider the use of sedation and or restraint to feed Ms L. He was asked for his expert assessment of her best interests in providing or withholding nutrients against her wishes.

44. Dr. C's expert opinion is forthright and unchallenged: Ms L is critically ill; if she were to be forcible fed via either NG tube or a PEG (percutaneous endoscopic gastrostomy) she would have to be sedated. Ms L's frail physical condition and compromised liver function means that the likelihood of death if force feeding were to be attempted on a chemically sedated basis would run at close to 100%. In the unlikely event that she were to survive she would he says, suffer severe physical and psychological consequences.

45. Dr Danbury concluded that sedation or restraint for the purposes of enforced feeding would be disproportionate and would only worsen Ms L's long term physical and psychological state. Dr Danbury has reviewed the literature and cannot find any reports of patients with a BMI as low as Ms L surviving enforced refeeding whilst sedated in intensive care.

46. Ms L is now in the final stages of her illness. As previously described she is in end stage organ failure: on the amount of nutrients she is willing to take she will continue to lose weight and die even if she does not die as a consequence of a sudden cardiac attack in the meantime which, due to her low BMI, is a high risk in itself. Dr Danbury's assessment in relation to force feeding is that it could only be achieved with sedation which it in itself would be likely to lead to her death.

47. In assessing the proposed declarations I have to the forefront of my mind that Ms L finds the idea of force feeding extremely distressing. Taking into account the level of Ms L's distress and the evidence of Dr Danbury I instinctively pull back from the prospect of sanctioning any proposal which may mean that, what may be Ms L's last conscious moments, are filled with the fear of being forced to take in hated calories.

48. The only remote possibility of Ms L now surviving would be if she agreed to increase her calorific intake and even then it is almost certainly too late to save her given the damage to her organs. Dr A her treating psychiatrist says that whilst Ms L has an intellectual understanding of the outcome she remains *'unmotivated to achieve recovery and is reluctant to engage in any form of psychological intervention which could promote this. Likewise she is not*

currently in a physical state whereby any such psychological treatment other than supportive care could be offered'

49. Dr Glover is clear that Ms L does not want to die. Intellectually she knows that she is close to death but as Dr Glover put it whilst she understood the risk of death she shows an inappropriate indifference to matters of life and death and it seems as if it has not entirely hit home. Dr B said that at an intellectual level Ms L understands she is close to death but she has no deep understanding of her position.

50. Recently a second nursing home has agreed to take Ms L if she was well enough. Ms L really wants to go there; in the past it may have been hoped that the prospect may have provided the incentive she needs to start putting on weight but, as Dr Glover points out her illness won't even let her increase her intake by 1ml an hour in order to help her towards that goal. Even if there was a 1% chance of her agreeing to increase her input, Dr Glover is of the view there is a *0.1% chance of her being able to stick to it and consistently to work to her recovery* he put it that way not in anyway to provide a true statistical assessment but to underline just how unlikely it is that after 16 years of struggle, Ms L will now be able to agree to be consistently refed. Only in the last few days Ms L has indicated that she cannot countenance an increase in nutrients as she is confined to bed and she cannot contemplate any calorific increase until she is walking around and able to "use some of them up".

51. Dr Glover and Dr B do not believe that Ms L now has long to live. Given her amazing resilience over the years it is impossible to put a time scale on her life expectancy, it is however likely to be measurable in weeks not months. Ms L

is in considerable pain. All agree that that is wholly unacceptable. Anything which can be done to make her comfortable and reduce her distress must be done. Morphine causes respiratory suppression and may further reduce her limited life expectancy but at this stage of her illness there can be no question that the absolute priority is to make her comfortable and pain free.

Capacity

52. On 9 July 2012 a request was made to assess Ms L's capacity following her refusal of oral dextrose treatment. Those assessments together with the assessment of Dr A, all concluded that Ms L lacks capacity with regard to treatment options available for her anorexia nervosa on the basis that she is unable to weigh up the risks and benefits of such treatment including her spontaneous and recurrent hypoglycaemic episodes.

53. Dr Glover, from the perspective of his particular expertise in the most severe forms of anorexia nervosa, considered the effect of anorexia nervosa on capacity both in his written report and again in evidence. Ms L's judgment is critically impaired by a profound and illogical fear of weight gain.

54. The illness, he explained, causes a deficit in capacity specific to issues relating to food and weight gain. A sufferer may otherwise appear perfectly rational and may well be able to make appropriate capacitous decisions about a range of issues e.g. relating to financial matters. More specifically in Ms L's case it is agreed that she has capacity to decide whether to take antibiotics for her pneumonia, the antibiotics are not calorific so she is able to make a perfectly rational decision that she needs antibiotics to fight off the infection which

would otherwise, in all likelihood, kill her. Similarly she has the capacity to consent to pain relief and treatment for her pressure sores.

55. Dr Glover also explained that it is a recognised effect (counterintuitive though it may seem) of profound malnutrition of the type seen in Ms L, that the fear of weight gain increases as body mass index falls; the examples given to me in evidence of Ms L's fear of weight gain and in particular her reaction to the prospect of only a 1ml per hour increase in her nutrient intake, amply confirms Dr Glover's evidence.

56. Having read the papers and heard Dr Glover give evidence I am entirely satisfied that Ms L does not have the capacity to make decisions in relation to serious medical treatment and in particular nutrition and hydration and the administration of dextrose for hypoglycaemic episodes. Given the unusual effect of the anorexia nervosa which results in Ms L having capacity in relation to some aspects of medical treatment and not in others it has been agreed that to avoid any future confusion there should be a further declaration that Ms L does retain capacity to make decisions as to antibiotic treatment and analgesia and treatment for her pressure sores.

Best Interests

57. Having concluded that pursuant to s1 MCA, Ms L is *unable to make a decision for herself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain* namely her anorexia nervosa, it falls to the court, pursuant to s4 MCA 2005 to determine what is in Ms L's best interests. In carrying out that exercise the court must consider all the relevant circumstances and take the following steps:

i) Consider whether and if so when, it is likely that Ms L will have capacity. ((s4(2))

ii) So far as reasonably practicable , permit and encourage Ms L to participate as fully as possible in the decision and take into account her wishes and feelings, beliefs and values (s4(4) and(6))

iii) This determination relating as it does to life sustaining treatment, must not be motivated by a desire to bring about Ms L's death (s4(5))

iv) Take into account the views of Ms L's family and carers as to what would be in Ms L's best interests and her wishes, beliefs and values.

Recovery of capacity:

58. On the evidence I have heard it is highly unlikely that Ms L will recover capacity, her chances of survival are slight and as her BMI drops ever lower she becomes ever more fixed on avoiding weight gain.

Participation in the decision/ Ms L's wishes and feelings

59. Ms L has played no part in the hearing but I have heard her views through the conduit of Dr Glover, of Mr Beck the official solicitors' representative and Mrs L described by Dr Glover as Ms L's "fantastic advocate". As already stated Ms L does not wish to die, she wishes to 'get stronger' and move to a nursing home. Unhappily however that seemingly rational desire is completely overwhelmed by her terror of gaining weight and by her fear of 'calories'. Dr Glover told the court that Ms L's wishes and feelings about her current and future treatment are excessively influenced by her anorexic condition. Her overriding, almost sole concern is with regard to nutritional intake and weight.

60. The court has also heard her wishes through her own record of 27 July 2012. One of the tragedies of the case is that whilst this record shows unequivocally that Ms L has not given up on life and still sees some sort of future for herself, on another level it reveals her resistance to oral food and is hopelessly unrealistic as to how long it would take before she was 'back on her feet'. Pursuant to these expressed wishes a few days later Ms L was put on a NG tube for feeding but she was unable to resist tampering with the tube and could not bring herself to agree to a calorific intake which would allow her to put on any weight let alone such as would result in her becoming well enough to move to a nursing home.

Motivation

61. A wish to bring about Ms L's death plays no part in any consideration of what is now in her best interests. No one wishes Ms L to die: her family have spent sixteen years trying to help her recover and experts in eating disorders all over the country have tried everything possible to avoid the now inevitable outcome. A wish to bring about death is however very different from a careful analysis of the realities of Ms L's situation and a recognition of the fact that, as described by Dr Glover, that time has come to cease active and invasive treatment and that her best interests now require the medical team to concentrate on causing her the least possible distress, ensuring that she is pain free and preserving her dignity. I bear in mind the words of Lord Goff in *Bland.*

The views of the family

62. Mrs L spoke most movingly to the court, she described how, when Ms L was first taken into hospital aged 14, they believed that after 3 or 4 months

treatment she would be well again and that nearly16 years later she 'never thought it would come to this.' Mrs L was clear that she did not think it would be in Ms L's best interests to be fed forcibly and wished to be involved in any discussions which would inform palliative and end stage care for her daughter. Dr B, who was present in court, reassured the family that that would be the case.

Medical Opinion

63. I have incorporated the medical opinion into the body of this judgment, it can be summarised as follows: (taken from Dr Glover's report)

i) Ms L has an extremely rare, severe and unremitting form of anorexia nervosa

ii) Ms L has been treated for the last six years in specialist eating disorder units which are nationally recognised as having expertise in the management of this condition. Despite this she has made no progress

iii) The prospects of her recovery overall approach zero

iv) Ms L is now showing signs of irreversible multi organ failure and she is drawing towards the end of her life.

v) In the light of the above it is imperative that treatment is directed towards maintaining her dignity and quality of life so far as possible. It is not acceptable for Ms L to endure serious pain during what may be the last days of her life.

vi) Given that it is extremely unlikely that Ms L will recover from her anorexia it is not in her best interests to make attempts to reverse her weight loss which require coercion, restraint or sedation. Dr Glover in particular felt no pressure should be put on Mrs L to seek to persuade or coerce Ms L into agreeing to increase her nutrient intake; Ms L is very close to her mother who has throughout been her most powerful advocate, Ms L must continue to see her mother as being 'on her side' and there must be no risk of Ms L feeling that now, at the end, her mother is in any way 'against her' by trying to force her to do something which her illness prevents her from doing.

Future treatment and the right to life

64. During the course of the day all the parties worked together to arrive at treatment plan for Ms L which each believe to be in her best interests. The day was long, at times very emotional; it can not have been otherwise than deeply traumatic for the family. On behalf of the Official Solicitor, and therefore Ms L, the evidence was challenged in relation to such issues as to whether she may yet feel able to contemplate increasing the amount of nutrients she is given. Having heard evidence and discussions having taken place through out the day with the parties having the advice and guidance of Dr Glover and Dr B throughout, the court was given a draft which was commended to the court by all parties. The proposed declarations are predicated on the basis that Ms L is in the closing stages of her life and that force feeding is not in her best interests. The proposed declaration aims to alleviate distress and pain and allow Ms L to die with dignity with her family around her.

65. The fact that all parties believe that the proposed declarations are in Ms L's best interests does not relieve the court from balancing all the relevant factors and coming to its own conclusion as to what is in the best interests of Ms L.

66. In carrying out the balancing exercise I bear in mind that our law contains a strong presumption that all steps will be taken to preserve life save in exceptional circumstances, this is reflected in Article 2 EHCR. The principle is not however absolute as Lord Goff recognised it in *Bland* and is amplified in the MCA Code of Practice 5.31:

> "*All reasonable steps which are in a 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*"

67. Dr Glover concluded his report by saying *there comes a point in the treatment of any patient where, regardless of the diagnosis, the slavish pursuit of life at any cost becomes unconscionable. I believe, sadly, that this point has been reached in Ms L's treatment.*

68. In my judgment this is one of those few cases where the only possible treatment, namely force feeding under sedation, is not to be countenanced in Ms L's best interests: to do so would be futile, carrying with it a near certainty that it would cause her death in any event. Such a course would be overly burdensome in that every calorie that enters her body is an enemy to Ms L.

69. Ms L would I am satisfied be appallingly distressed and resistant to any suggestion that she was to be force fed and to what purpose? Her poor body is closing down, organ failure has begun, she can no longer resist infection and

she is, at all times in imminent danger of cardiac arrest. Even if she could, by some miracle, agree to some miniscule increase in her nutrient intake her organ failure is nevertheless irreversible and her anorexia so severe and deep rooted that there could be no real possibility of her maintaining her co-operation. Ms L on occasion shows some small spark of insight – she said on the 1st August that she was frightened as she cannot help herself from "messing with the tube".

70. In all the circumstances therefore I have concluded that it is in Ms L's best interests for me to make declarations in the terms set out in the agreed draft. The draft allows for the faint hope that even now Ms L may 'turn the corner' but recognises and addresses the far more likely outcome.

71. I accordingly make orders and declarations in the following terms:

UPON the NHS Trust agreeing to continue to involve the family of L in discussions about L's future clinical care including any decisions to move to a solely palliative care plan.

AND UPON the Court having made a reporting restrictions order in respect of this matter.

***IT IS HEREBY DECLARED THAT**:*

1. *L lacks capacity to:*
    (a) litigate; and
    (b) make decisions in relation to the serious medical treatment at issue in this application. Specifically in relation to whether or not to refuse:
        i. nutrition and hydration, and
        ii. dextrose for hypoglycaemic episodes.

2. *L has the capacity to make decisions as to anti-biotic treatment, analgesia and treatment of her pressure sores.*

3. *The following being in L's best interests, the applicant's clinicians shall be permitted:*

(a) *to provide nutrition and hydration and medical treatment (including treatment for hypoglycaemia) to L in circumstances where she complies with that administration, including where nutrition and/or hydration is delivered by means of a naso-gastric tube;*

(b) *to administer dextrose solution to L by oral or intravenous route despite her objections where, in the opinion of the treating clinicians, such administration is immediately necessary to save the life of L provided that such treatment is administered using the minimal degree of force practicable and necessary to achieve the same, and at all times taking such steps as can be taken to ensure that L suffers the least distress and retains the greatest dignity. Save that there be permission not to insert or leave a central line in situ in anticipation of peripheral access being unobtainable.*

(c) *not to provide L with nutrition and hydration with which she does not comply where such treatment cannot be delivered without her co-operation and/or without the use of physical force.*

i. *For avoidance of doubt the above declaration shall be of effect notwithstanding that in the opinion of the treating clinicians, it would be immediately necessary to administer such nutrition to preserve the life of L;*

ii. *Save that the above declaration shall only be of effect if all reasonable steps have been taken to gain L's co-operation (having regard to the distress such steps may cause L) through the use of appropriate verbal explanations and persuasion including, where appropriate, involving her parents, or such other person in whom she might have some trust, in attempts to persuade L to accept the said interventions.*

(d) *Should L condition further deteriorate such that in the opinion of the treating clinicians she has entered the terminal stage of her illness, to provide L with such palliative care and related treatment (including pain relief and anxiolytics) under medical supervision to ensure that L suffers the least distress and retains the greatest dignity until such time as her life comes to an end.*