Case No: FD02P00072

**[2002] EWHC 429 (Fam)**
**IN THE HIGH COURT OF JUSTICE**
**FAMILY DIVISION**

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22nd March 2002.

**Before** :

**THE PRESIDENT**

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**Between :**

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|---|---|
| **Ms B** | **Applicant** |
| **- and -** | |
| **An NHS HOSPITAL TRUST** | **Respondent** |

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**Mr Philip Havers QC and Mr Jeremy Hyam** (instructed by **Leigh Day and Co.**) for the Applicant
**Mr Robert Francis QC and Mr Michael Horne** (instructed by **Capsticks**) for the Respondent

**Mr Peter Jackson QC** for **the Official Solicitor**

Hearing dates : 6/7/8th March 2002

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# 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.

.............................
Dame Elizabeth Butler-Sloss, P.

This judgment is being handed down in public on 22nd March 2002. It consists of 31 pages signed and dated by the judge together with the injunction, consisting of 2 pages, granted in respect of publicity.

*Order in Open Court*

# IN THE HIGH COURT OF JUSTICE
## FAMILY DIVISION
## PRINCIPAL REGISTRY

Before the Right Honourable DAME ELIZABETH BUTLER-SLOSS The President

**In the matter of the Inherent Jurisdiction of the High Court**

**And in the matter of Ms B**

Between **Ms B** Claimant

and **An NHS HOSPITAL TRUST** Defendant

On the 22nd day of March 2002

**UPON HEARING leading counsel and junior counsel for the Claimant, leading and junior counsel for the Defendant and leading counsel for the Official Solicitor**

**AND UPON READING the papers filed herein**

**IT IS ORDERED THAT:-**

1. No written or photographic material shall be published or broadcast in any form whatsoever (save solely on a strictly confidential basis to any persons from whom the Claimant wishes to receive advice) to any persons whether in writing or electronically from which any of the following could be identified as being connected with these proceedings:-

   (a) The Claimant;

   (b) Any members of the Claimant's family or friends;

***(continued overleaf)***

(c) The Defendant NHS Trust;

(d) A hospital in which the Claimant is being cared for or in which it is or has been proposed that she be cared for in the future;

(e) Any person caring for or treating the Claimant or whom it is proposed shall care for or treat her in future;

(f) Any person who gives evidence in these proceedings whether written or oral except Dr.T.Sensky.

2. This Order, unless varied by the Court, shall continue to have effect notwithstanding the death of Claimant.

3. There be liberty to any person affected by this Order to apply to vary or discharge it.

## Dame Elizabeth Butler-Sloss, P. :

1. The Claimant, whom I shall call Ms B, seeks declarations from the High Court in its exercise of the inherent jurisdiction. She claims that the invasive treatment which is currently being given by the respondent by way of artificial ventilation is an unlawful trespass.

2. The respondent is the NHS Hospital Trust (the Trust) responsible for the hospital which is currently caring for Ms B, (the Hospital). At the request of the court the Official Solicitor instructed Mr Peter Jackson QC to act as Advocate to the Court. The main issue is whether Ms B has the capacity to make her own decision about her treatment in hospital. Underlying this important issue is the tragic story of an able and talented woman of 43 who has suffered a devastating illness which has caused her to become tetraplegic and whose expressed wish is not to be kept artificially alive by the use of a ventilator.

### The History

3. Ms B was born on the 6th August 1958 in Jamaica, and has lived in the United Kingdom since the age of 8. She had an unhappy childhood but triumphed over many difficulties to achieve a degree in Social Science and Social Work, and a Masters degree in Public Policy and Administration. She is a qualified Practice Teacher for Social Work, and has a Management Diploma from a London College. She worked as a social worker for a number of local authorities and became a Team Manager. She was appointed in that role to a hospital and was promoted to Head of Department and Principal Officer for training and staff development. She is unmarried. She has a close circle of friends and a godchild to whom she is devoted.

### Medical History

4. On the 26th August 1999, Ms B suffered a haemorrhage of the spinal column in her neck. She was admitted to the Hospital and a cavernoma was diagnosed, a condition caused by a malformation of blood vessels in the spinal cord. She was transferred to another hospital where she stayed for five weeks. She was informed by doctors that there was a possibility of a further bleed, or surgical intervention, which would result in severe disability. On the basis of this advice she executed a Living Will (dated 4th September 1999). The terms of the Will stated that should the time come when Ms B was unable to give instructions, she wished for treatment to be withdrawn if she was suffering from a life-threatening condition, permanent mental impairment or permanent unconsciousness. She was, however, also told that the risk of re-haemorrhage was not particularly great, and so she felt very optimistic about the future. Her condition gradually improved and after leaving hospital and a period of recuperation, she returned to work. Thereafter Ms B was in generally good health although she had some continued weakness in her left arm.

5. At the beginning of 2001, Ms B began to suffer from general weakening on the left side of her body, and experienced greater numbness in her legs. She felt unwell on the 12th February 2001, and was admitted to the Hospital in the early hours of the 13th February 2001. She had suffered an intramedullary cervical spine cavernoma, as a result of which she became tetraplegic, suffering complete paralysis from the neck down. On the 16th February 2001 she was transferred to the Intensive Care Unit (the ICU) of the Hospital. She began to experience respiratory problems, and was treated with a ventilator, upon which she has been entirely dependent ever since.

6. Ms B told Dr R (a consultant anaesthetist in the ICU of the Hospital) and another consultant anaesthetist on about the 24th February 2001 that she had a Living Will on file, and did not want to be ventilated. The doctors informed her that the terms of the Living Will were not specific enough to authorise withdrawal of ventilation. On the 23rd March 2001 at another hospital she underwent neurological surgery to remove the cavernous haematoma. After the operation, her condition improved slightly. She regained the ability to move her head, and to articulate words. She was however, as she said, bitterly disappointed that the operation had not been more successful. It was at that time that she first asked for the ventilator to be switched off.

7. On the 26th March 2001 she was assessed by Dr RG, a consultant psychiatrist from another hospital. On the 28th March 2001 Ms B was returned to the ICU at the Hospital where she remains. She made a request to a consultant anaesthetist to have the ventilator switched off. On the 5th April 2001, Ms B gave formal instructions to the Hospital, via her solicitors, that she wished the artificial ventilation to be removed. The Trust got in touch by telephone with its solicitors, Capsticks, who replied by a letter to the Head of External Relations. I shall return to that letter later in this judgment. A case conference followed and it was arranged that two independent psychiatric assessments would be conducted before any further steps were taken.

8. On the 10th April 2001 she was assessed by Dr L, a consultant psychiatrist at the Hospital, who concluded she had capacity. On the 11th April 2001 she was assessed by another consultant psychiatrist at the Hospital, Dr E, who initially found that Ms B did have capacity. Dr E on the 12th April 2001 then amended her report to state that Ms B did *not* have capacity, after which Dr L amended his original assessment so as to agree with Dr E. After Dr E's initial opinion, preparations had begun to be made for the ventilator to be turned off. Ms B held discussions with one of the doctors and a lead nurse of the Hospital, and it was agreed that three days should be allowed for Ms B to say goodbye to her family and friends and to finalise her affairs. However, these preparations were called off after Dr E changed her report.

9. Ms B was prescribed antidepressants on the 13th April 2001. She was seen by both Dr E and Dr R on the 30th April 2001. Both doctors stated that on this occasion Ms B said that she was relieved the ventilator had not been switched off. On the 29th May 2001, Ms B participated in assessment for rehabilitation, and agreed to try it. Long-term plans were made for her rehabilitation, with a view to eventually returning home with 24-hour care, or alternatively a residential nursing home. Dr R gave evidence that on the 29th May 2001 Ms B, having been visited by the rehabilitation specialists, was

"very cheerful" and "upbeat". She was referred to several spinal units. She received help, which is continuing, from a clinical psychologist. She was re-assessed on the 29th June 2001 by Dr L, and on the 4th July 2001 by Dr E. Their assessments did not provide a firm conclusion as to her mental capacity. On the 12th July 2001 a bronchoscopy was carried out as part of treatment for a left lung collapse. At her request, an independent re-assessment was conducted by Dr RG on the 8th August 2001. He indicated that he did not consider her to be suffering from depression and that he considered her competent to make the decision to discontinue her treatment. Thereafter the Hospital treated Ms B as having capacity to make decisions.

## 8th August to the Hearing

10. Ms B made a further Living Will on the 15th August 2001. On the 12th and 25th September two further bronchoscopies were performed with Ms B's consent. She was suffering respiratory distress at the time. The Medical Director considered that there should be involvement from an ethics committee and that assistance should be sought from outside. The Trust did not have an ethics committee and the Health Authority was unable to consider the problem. Between August 2001 and the issue of these proceedings by Ms B on 16 January 2002 the Trust sought advice from various outside sources. The possibility of a one-way weaning programme was suggested by Dr S, a consultant in neuroanaesthesia and intensive care from another hospital who was consulted. One-way weaning is a programme whereby over a period of time the number of breaths supplied by the ventilator is gradually reduced and the patient's body is allowed to become used to breathing on its own again. Generally if the patient cannot manage on his/her own then the number of breaths is increased. In a one-way weaning programme it would be reduced without going back on the support. Sedation would be given but not so as to cause respiratory depression unless clinically indicated. The clinicians were not prepared to turn off the ventilator. The one-way weaning programme was agreed by the clinicians but with reluctance as an acceptable compromise. It was also agreed that this could be achieved either by sending Ms B to a weaning centre or carrying it out in the ICU.

11. On the 12th November Ms B was offered referral to a weaning centre which she rejected. In the alternative she was offered the programme in the ICU. This she also rejected for two reasons, being the length of the process (about three weeks), and the omission of pain killers as part of the treatment. Ms B made it clear from September 2001 that she did not want to go to a spinal rehabilitation unit. She refused the possibility of a referral to one clinic when her name was near the top of the waiting list in October. She also refused the possibility of a bed in a hospice in December since the hospice would not accept her wish to have her ventilator withdrawn.

## The Issues

12. Mr Havers QC, for Ms B, has not, for the purpose of this hearing, challenged the conclusions of the psychiatrists as to her lack of mental capacity between April and August 2001 and it is not necessary for me to consider her ability to make decisions before the 8th August. Although her capacity was not challenged by the treating

doctors after the 8th August nor was she again examined by a psychiatrist before the commencement of these proceedings, Mr Francis QC, for the Trust, does not accept that Ms B did have capacity from the 8th August nor that she has it now. I shall therefore have to consider in some detail her ability to make decisions and in particular the fundamental decision whether to require the removal of the artificial ventilation keeping her alive. It is important to underline that I am not asked directly to decide whether Ms B lives or dies but whether she, herself, is legally competent to make that decision. It is also important to recognise that this case is not about the best interests of the patient but about her mental capacity.

13. The issues are therefore

a) Does the Claimant, Ms B, have the mental capacity to choose whether to accept or refuse medical treatment, in circumstances in which her refusal will, almost inevitably lead to her death? If the answer is yes,

b) Did she have the capacity to choose from August 2001?

Ms B seeks declarations from the court in respect of both questions.

c) If the answer to (b) is yes, then Ms B seeks a declaration from the court that the Hospital has been treating her unlawfully from the 8th August 2001.

d) If the answer to (b) is yes, then Ms B also seeks nominal damages to recognise the tort of trespass to the person.

e) It will be necessary to continue injunctions in relation to publicity.

## The law on mental capacity

14. The general law on mental capacity is, in my judgment, clear and easily to be understood by lawyers. Its application to individual cases in the context of a general practitioner's surgery, a hospital ward and especially in an intensive care unit is infinitely more difficult to achieve.

15. In a series of cases during the 1990s the House of Lords and the Court of Appeal restated the long-established principles which govern the law on mental capacity of adults and provided some guidelines in complex medical situations.

## a. The principle of autonomy

16. In 1972 Lord Reid in *S v McC: W v W* [1972] AC 25 said, at page 43

> "… English law goes to great lengths to protect a person of full age and capacity from interference with his personal liberty. We have too often seen freedom disappear in other countries not only by coups d'état but by gradual erosion: and often it is the first step that counts. So it would be unwise to make even minor concessions."

17. In *re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, Lord Goff of Chieveley said at page 72

> "I start with the fundamental principle, now long established, that every person's body is inviolate."

18. Lord Donaldson of Lymington, MR said in *re T (Adult: Refusal of Treatment)* [1993] Fam. 95, at page 113

> "…. . the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent."

19. In *re T (Adult: Refusal of Treatment)*, I cited Robins JA in *Malette v Shulman* 67 DLR (4th) 321 at 336, and said at page 116-117

> "The right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based. Free individual choice in matters affecting this right should, in my opinion, be accorded very high priority."

20. In *re MB (Medical Treatment)* [1997] 2 FLR 426, I said at 432

> "A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death", (referring to *Sidaway v Board of Governors of the Bethlehem Royal Hospital and the Maudsley Hospital* [1985] A.C. 871, per Lord Templeman at 904-905; and to Lord Donaldson M.R. in *re T (Adult: Refusal of Treatment*) (see above)).

21. This approach is identical with the jurisprudence in other parts of the world. In *Cruzan v Director, Missouri Department of Health* (1990) 110 S. Ct 2841, the United States Supreme Court stated that

> "No right is held more sacred, or is more carefully guarded… than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."

### b. The sanctity of life

22. Society and the medical profession in particular are concerned with the equally fundamental principle of the sanctity of life. The interface between the two principles of autonomy and sanctity of life is of great concern to the treating clinicians in the present case. Lord Keith of Kinkel in *Airedale NHS Trust v Bland* [1993] AC 789, said at page 859

> ".. the principle of the sanctity of life, which it is the concern of the state, and the judiciary as one of the arms of the state, … is not an absolute one. It does not compel a medical practitioner on pain of criminal sanctions to treat a patient, who will die if he does not, contrary to the express wishes of the patient."

23. Lord Goff of Chieveley said at page 864

> "First, it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so… To this extent, the principle of the sanctity of human life must yield to the principle of self-determination (…), and for present purposes perhaps most important, the doctor's duty to act in the best interests of his patient must likewise be qualified. On this basis, it has been held that a patient of sound mind may, if properly informed, require that life support should be discontinued: see *Nancy B v Hôtel-Dieu de Québec* (1992) 86 DLR (4th) 385…. I wish to add that, in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to do, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient's wishes."

24. Lord Mustill said at pages 891 and 1062

> "Any invasion of the body of one person by another is potentially both a crime and a tort….
>
> How is it that, consistently with the proposition just stated, a doctor can with immunity perform on a consenting patient an act which would be a very serious crime if done by someone else? The answer must be that bodily invasions in the course of proper medical treatment stand completely outside the criminal law. The reason why the consent of the patient is so important is not that it furnishes a defence in itself, but because it is usually essential to the propriety of medical treatment. Thus, if the consent is absent, and is not dispensed with in special circumstances by operation of law, the acts of the doctor lose their immunity…..
>
> Even if the patient is capable of making a decision whether to permit treatment and decides not to permit it his choice must be obeyed, if on any objective view it is contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse circumstances and even death will or may ensue."

25. In the *Bland* case the issue concerned a patient in the permanent vegetative state. In *re T (Adult: Refusal of Treatment*) (see above) the issue was the state of competence of a pregnant young woman who had been injured in a car crash and was refusing a blood transfusion. Lord Donaldson of Lymington M.R. said at page 112

> "This situation gives rise to a conflict between two interests, that of the patient and that of the society in which he lives. The patient's interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount."

26. I note with interest that a situation similar to that of Ms B was considered by the Quebec Superior Court in *Nancy B v Hôtel-Dieu de Québec et al.* (1992) 86 DLR (4th) 385, in which a competent 25 year old woman with an incurable neurological disorder sought an injunction to enforce her refusal of artificial ventilation, without which she was incapable of breathing independently. The court in that case decided that the plaintiff was entitled to the injunction sought, and ordered that the treating doctor be permitted to stop ventilation if and when the plaintiff so instructed.

27. In the evidence of Dr I, to which I refer later in this judgment, he said that, in his view, the principles of autonomy and beneficence would appear to be in conflict in this case. In accordance with the principle set out so clearly by Lord Mustill and Lord Donaldson (above), the right of the competent patient to request cessation of treatment

must prevail over the natural desire of the medical and nursing profession to try to keep her alive.

## c. The presumption of mental capacity

28. There is a presumption of capacity

> "Every person is presumed to have the capacity to consent to or to refuse medical treatment unless and until that presumption is rebutted." (*Re MB (Medical Treatment)* (Court of Appeal) [1997] 2 FLR 426, at page 436, per Butler-Sloss LJ).

## d. Assessing capacity

29. In looking at this most difficult exercise which has to be carried out regularly by the medical profession and only occasionally by the judiciary, it is instructive to read a passage in the opinion of Justice Steffen in *McKay v Bergstedt* (1990) 801 P ed 617 (Nev Sup Ct) 2, at page 5

> "One of the verities of human experience is that all life will eventually end in death. As the seasons of life progress through spring, summer and fall, to the winter of our years, the expression unknown to youth is often heard evincing the wish to one night pass away in the midst of a peaceful sleep. It would appear, however, that as the scientific community continues to increase human longevity and promote "the greying of America" prospects for slipping away during peaceful slumber are decreasing. And for significant numbers of citizens like Kenneth, misfortune may rob life of much of its quality long before the onset of winter."

30. In that case Kenneth was 31 years old and had been tetraplegic since the age of 10. As a result of the imminent death of his father who had cared for him, Kenneth wanted to be released from

> "a life of paralysis held intact by the life-sustaining properties of a respirator."

31. Lord Donaldson of Lymington M.R. in *re T (Adult: Refusal of Treatment)* (above) said at page 113

> "What matters is that the doctors should consider whether at [the relevant time] he [the patient] had a capacity which was commensurate with the gravity of the decision which he purported to make. The more serious the decision, the greater the capacity required."

32. And he summarised the position at page 115-116

> “ (1) [is largely set out in the passage above]
>
> (2) An adult patient may be deprived of his capacity to decide either by long term mental incapacity or retarded development or by temporary factors such as unconsciousness or confusion or the effects of fatigue, shock, pain or drugs.
>
> (3) If an adult patient did not have the capacity to decide at the time of the purported refusal and still does not have that capacity, it is the duty of the doctors to treat him in whatever way they consider, in the exercise of their clinical judgment, to be in his best interests.
>
> (4) Doctors faced with a refusal of consent have to give very careful and detailed consideration to what was the patient’s capacity to decide at the time when the decision was made. It may not be a case of capacity or no capacity. It may be a case of reduced capacity. What matters is whether at that time the patient’s capacity was reduced below the level needed in the case of a refusal of that importance, for refusals can vary in importance. Some may involve a risk to life or of irreparable damage to health. Others may not.”

33. In *re MB (Medical Treatment)* the Court of Appeal adopted the criteria set out by Thorpe J in *re C (Adult)(Refusal of Treatment)* [1994] 1 WLR 290 at 295, and I said at page 437

> “A person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment. That inability to make a decision will occur when:
>
> a) the person is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
>
> b) the patient is unable to use the information and weigh it in the balance as part of the process of arriving at a decision.”

34. In *Bartling v Superior Court of Los Angeles County* (1984) 163 Cal. App. 3d 186, the superior court had to consider the issue of ambivalence. It held that the patient’s previous ambivalence about withdrawal of treatment was not relevant to the assessment of his capacity

> “The fact that [a patient] periodically wavered from this posture [ie, preferring death to his intolerable life on the

> ventilator] because of severe depression or for any other reason does not justify the conclusion of [the hospital] and his treating physicians that his capacity to make such a decision was impaired to the point of legal incapacity." *Lane v Candura* (1977) N.E.2d 1232, 1234, fn3 referred to.

35. In my view, ambivalence may be relevant if, and only if, the ambivalence genuinely strikes at the root of the mental capacity of the patient. As I have already said the principles are clear and, in certain cases, their application to the individual case may be extremely difficult. To resolve disputed issues of capacity, as a last resort, there may have to be an application to the High Court for guidance.

36. I turn now to the evidence called before me.

## The evidence of Ms B

37. I heard the evidence of Ms B in a side ward of the ICU of the treating Hospital. She heard the remainder of the evidence through a video-conferencing link between the Royal Courts of Justice and the Hospital.

38. Her present situation is that she is paralysed from the neck down. She is conscious and capable of speech with the assistance of a speaking valve. She can move her head and use some of her neck muscles, but cannot move her torso, arms or legs at all. She is able to eat and drink. She is totally dependent on her carers, who feed, clothe and wash her and assist with her bodily functions. Her life is supported by artificial ventilation through a tracheostomy, a tube in her windpipe. Without the help of artificial ventilation, according to the medical evidence, she would have a less than 1% chance of independent ventilation, and death would almost certainly follow.

39. She provided two written statements and gave oral evidence for about an hour and a half. She gave a clear account of her wishes and her feelings. She made it clear in her written and oral evidence that she had never changed her view that she wanted the ventilator withdrawn. It was only during the period that she was assessed as not having capacity to decide that she agreed to consider other possibilities. For the purposes of this case I shall concentrate upon the issues of ambivalence over turning off the ventilator and her rejection of rehabilitation and the one-way weaning programme.

## Ambivalence

40. In her written statement Ms B said

> "I never changed my mind about wishing for the ventilator to be switched off with the inevitable consequence of death. Having expected the process towards death to be commenced, I

> was informed by the hospital that this would not now happen because of a change in psychiatric opinion that I no longer had capacity. … I was relieved to some extent by the fact that I would not have to deal with the undeniably stressful and difficult questions of saying goodbye to my friends and family. Although it is true that I felt some level of relief, at no stage did I feel that I either regretted my previous decision or wished to change my mind.”

41. In her oral evidence, she repeated that explanation, stating:

> “I did have some sense of relief, but it was not the sort of relief like, ‘I am really glad I am alive’, it was a sort of relief that I had a very difficult task ahead of me.”

42. She was asked why she had previously agreed to undergo bronchoscopies and said

> “Because if I had refused treatment, dying would have been similar to the ventilation – to being weaned. … it may have been very painful and slow.”

43. In her statement Ms B explained why she looked at the possibility of rehabilitation

> “At this stage I had not been assessed as having capacity so I agreed to giving rehabilitation a try”.

44. Ultimately, upon having her mental capacity accepted on 8 August, Ms B said that she

> “rejected this option of rehabilitation as it offered no possibility of recovery. I had not changed my views, it is just that now I was assessed as being able to make a choice.”

## One-Way weaning programme

45. In her written statement Ms B said

> “I have refused the specialist clinic because weaning is essentially a long term treatment for patients who want to live without ventilation. This is not what I want as it has no positive benefits for me given my level of disability. [The one way weaning programme] does not include pain control and would last for several weeks. … I have refused this option because this would be a slow and painful death and my view of this is not disputed by the doctors. I would also feel robbed of a certain amount of dignity. … My wish is to be sedated. I would expect it to be a quick and painless death and less distressing for my

> loved ones. Negative weaning [one-way weaning] would mean watching me die over a series of weeks, the thought of this is painful for me to accept."

46. In her oral evidence she said

> "My concern was that I would have a very long and uncomfortable, possibly painful, passage because the programme, as proposed to me, was not to gradually withdraw the ventilator, but to reduce it to a level where my ventilation would be inadequate. That would provide a situation where I would then develop a chest infection and, possibly, other complications, and then I would die from those complications. So, without being too graphic, I would actually be waiting to become septic. I have seen that happen and I know it is slow and I know it is painful. One of my other concerns is that I have experienced having sedation here for short procedures like when I had my lungs cleaned out, but I have also had sedation over a longer period during the earlier part of my illness when I was very ill. The type of sedation I had meant that I had very vivid dreams, was very disoriented and did not know where I was or what the nurses' roles were and was very frightened. I felt that if I was lightly sedated as part of the weaning program, and I lay here for a period of weeks, I would possibly go quietly psychotic, quite frankly, apart from the physical discomfort. That just terrified me, the prospect of dying like that, really."

## Ms B's wishes

47. She was asked by Mr Francis QC, for the Hospital, whether it was her wish to die, or not to remain alive in her present condition, she replied

> "The latter. .. Given the range of choices, I would want to recover and have my life back, or significant enough recovery to have a better quality of life. I am not convinced from the evidence that that is going to happen, and I find the idea of living like this intolerable."

> "My view [about rehabilitation] is that it offers me no real opportunity to recover physically, that, in actual fact, it will be more teaching me to live with my disability and to make use of the technologies available and that sort of thing, working with the carers. But, actually, I will not recover in any way. That is not acceptable to me."

48. She was asked by Mr Francis whether the independence gained through rehabilitation would be of value to her, and said,

> "I think it is an improvement, certainly. Whether it is sufficient for me or not is where we probably disagree. I don't think it is sufficient, but I can see that it offers opportunities for communication. …I think it does make a difference to quality of life, but I do not think it is sufficient for me to want to pursue it."

49. She was asked by Mr Francis what stopped her from trying rehabilitation before making up her mind and replied

> "There are two things. One, I know what it has to offer and I know that what I want it cannot offer. It offers me no chance of recovery. That is not disputed by anybody. Two, there has not been a place available anyway to try it. At a time when I was going through it here and would have tried it, there was no place. And I think there is a logistical problem that, once you go to rehab, if my views did not change, it would be extremely difficult to get to a position of having my ventilation withdrawn."

50. She expressed some views on the hospital and the present proceedings. She said

> "…I felt that I was being treated as if I was being unreasonable by putting people in this awkward position. I fully accept the doctor's right to say, 'I personally will not do it', and I respect that position, but I was angered at the arrogance and complete refusal to allow me access to someone that would. I felt my path was being blocked and I was being pressurised to accept this option, to quietly go away conveniently, even though at tremendous cost to me and my family…. I felt that my rights were being eroded and that is not something I tolerate really; it is not within my character to go along with that."

51. She was then asked whether it would make a difference to her views if she were able to access a place in the near future on a trial basis subject to subsequent review as to whether she wished to remain on ventilation or not. She said

> "Six months ago I think I would have tried it, but my mind is made up. I would not, out of choice, do that now. I think I have sufficient understanding of what is available to be able to make an informed decision. Six months ago I was judged not to have capacity. I would have tried anything. But I think I have more options now.
>
> I think people are disabled by their own feelings about this… That is a human response that I understand, but that is what I mean about being in professional mode and getting on with the difficult things you have to do."

52. At the end of her written statement she set out her feelings as a Christian

> "In many ways the decision to have my treatment withdrawn has been a very difficult one for me as I have been a Christian and a regular church attendee all my life. The dominant view in the church is that that I should wait for God to heal me. Withdrawing ventilation would be seen as throwing in the towel. I have questioned myself about this and it has challenged my integrity. It has been a very difficult process to rationalise what I am doing in the context of my faith but I feel there is no alternative, as I do not have any realistic hope of recovery. I have come to believe that people die and become disabled and God does not always intervene. It has also been difficult for me to contemplate leaving the people I love behind. There has been a lot of talking and crying as no one wants me to die but almost all of them empathise with me and my situation and sincerely wish to respect my wishes, which I have made clear to all."

53. Her wishes were clear and well–expressed. She had clearly done a considerable amount of investigation and was extremely well-informed about her condition. She has retained a sense of humour and, despite her feelings of frustration and irritation which she expressed in her oral evidence, a considerable degree of insight into the problems caused to the Hospital clinicians and nursing staff by her decision not to remain on artificial ventilation. She is, in my judgment, an exceptionally impressive witness. Subject to the crucial evidence of the consultant psychiatrists, she appears to me to demonstrate a very high standard of mental competence, intelligence and ability.

## The medical evidence

54. I heard oral evidence from five doctors. I also read other statements filed by the Trust and a further report from Dr S, to whom I referred above. It is not, in my view, necessary to set out anything further from the written evidence other than from Dr B to whom I have referred below. All the consultants, other than one whom I have named, either have been or may be in a clinical treating relationship with Ms B and, for that reason, none of them is identified in this judgment. Two consultant anaesthetists, Dr R and Dr C, who have been treating Ms B in the Hospital ICU, gave oral evidence.

## Dr R

55. She made a statement and gave oral evidence. She said that, on the request of Ms B to stop the ventilator she was not prepared to take that step in the way suggested. She accepted that from August 2001 Ms B had capacity and the right to withdraw treatment. She treated Ms B on the basis that she had capacity to make decisions. She asked for advice. Her main concern was for Ms B to be aware of all the options available. The position in the ICU was different from a rehabilitation clinic. The ICU was not an ideal place for decision-making.

56. She questioned whether there was ambivalence. The main dilemma was around the legal and ethical issues of turning off the ventilator. She had never had to discuss a decision such as this before or be in such a situation. Ms B was not a common day to day patient. She was very unusual. Dr R had treated her for a year and would find it very difficult to turn off the ventilator. After artificial ventilation for a period it would take a few days for the body to adjust to breathing normally. The attempt at one-way weaning was over a period of about three weeks and if not successful she would not be able to breathe unaided. But if the ventilator were switched off the end would be in a few hours. Immediate withdrawal would cause her death. She would be prepared to undergo the one-way weaning process and to sedate the patient to keep her calm. If there was no possibility of her breathing unaided Dr R said she would reduce the length of time of the weaning and increase the sedation. There was a dilemma over the one-way weaning process. In the past she had put patients back on the ventilator when it was necessary. She had agreed to the weaning process. She accepted Mr G's judgment as to the unlikelihood of Ms B being weaned off the ventilator and that staged weaning was irrelevant.

**Dr C**

57. She made a statement and gave oral evidence. She was the lead clinician and met regularly to discuss Ms B's case with the medical director of the Hospital. She made inquiries of a consultant from another hospital, (Dr D). He told her that it was a matter of consent. She felt that the clinicians always treated Ms B as competent to make decisions. It was however difficult for a patient to make a decision without experiencing a spinal rehabilitation unit. Her dilemma was not to be against the wishes of Ms B but to offer her anything to make her want to live. The four anaesthetists working in intensive care, Dr R, herself and two others discussed how they should approach this situation. It was very difficult and they were and continued to be put under tremendous pressure by the circumstances of this case. She had reluctantly gone along with the proposal of a one-way weaning process. If it was up to her she would not suggest or commence withdrawal of treatment from Ms B. She had studied and spent her professional life trying to do her best to improve and preserve life. She did not feel able to agree with simply switching off Ms B's ventilation. She would not be able to do it. She felt she was being asked to kill Ms B. They had all been looking after Ms B for a long time on a very intimate level. She felt that a lot more needed to be done for these patients.

58. It was clear from their evidence that both the treating clinicians were deeply distressed by the dilemma which had faced them over the year that Ms B had spent in the ICU. They knew her well and respected and liked her. They considered her to be competent to make decisions about her medical treatment. They could not, however, bring themselves to contemplate that they should be part of bringing Ms B's life to an end by the dramatic, (my word), step of turning off the ventilator. As I listened to the evidence of each of them I had the greatest possible sympathy for their position.

## Mr G

59. Mr G is a consultant surgeon in spinal injuries with particular experience of patients in a spinal rehabilitation unit unconnected with the Trust. He saw Ms B on the 8th February 2002 and made a report and gave oral evidence. He was very impressed by Ms B. She appeared able to understand everything he said and to respond appropriately to all questions. She did not appear to be depressed. She told him that she had asked for the ventilator to be withdrawn at an early stage as soon as she had been made aware of her prognosis. He discussed with her the various rehabilitation options. She appeared to have given considerable thought to her situation. She had done a great deal of research through the Internet. She said that she still wanted the ventilation to be withdrawn. She said

> "I have given it a fair try but I still feel the way I do."

60. Mr G considered that she was able to receive and retain information given by him. She was able to converse in a rational manner and to explain herself clearly and in an apparently balanced manner. She was able to weigh the information in order for her to reach a decision. He said in his report that

> "My main reservation in relation to the above three questions can be seen in the records. At certain times she enjoys herself and is glad that she is alive. At other times she expresses a wish that the ventilator should be switched off. I am, therefore, concerned that her wish to have the ventilator switched off stems not so much from a wish to be dead, as from her wish to be free from all that surrounds her current condition. I consider this is a most important aspect as I have seen it before in different forms and have seen patients change their minds. This change of mind is not usually a sudden event but rather an evolution of understanding and insight as the person comes to appreciate in greater depth the value of life to them. This tends to arise most often as the person leaves hospital for life in the community."

61. He discussed some of those issues with Ms B who pointed out that she did not have a supportive family and might find herself on her own with carers or in a nursing home. He accepted that she was permanently ventilator dependent and in his opinion she would never be weaned from the ventilator. He considered that she had not experienced the full range of environmental control systems. She might be aware of what was possible but she had not experienced what could be done. He felt that the sooner she could be admitted into a comprehensive spinal cord injury centre the better in order to experience the modern approaches and to meet other patients in a similar position to her. She would be able to go out into the community. Although the ICU looked after her extremely well, ICUs were very abnormal environments for persons who were otherwise well such as Ms B.

62. He was aware from his personal experience and from research he had carried out in 1984 that there were several patients who had expressed the wish to die whilst in the acute phase following their injury but then changed their mind later and were grateful that their wishes expressed earlier were ignored. He drew the attention of the court to his article in the British Medical Journal, (December 1985, page 1620) entitled "Ventilation or dignified death for patients with high tetraplegia." He accepted that none of the patients in his study had gone home still dependent on a ventilator. In his view patients needed to experience those aspects in order to know what life would be like. He disagreed with Ms B's view to the contrary. From his experience he doubted that she could come to a fully informed decision without having actually experienced what was possible. The wish to be off the ventilator reflected the total indignity, lack of control and frustration that emanated from their severe disability rather than a specific wish for death. When such patients left hospital and went into the community and experienced life, the majority found that life was valuable to them. Perhaps surprisingly most ventilator dependent patients took a very positive view on life. He felt that time was a factor; time, appropriate environment and exposure to the technology available. He thought that it would take up to two years to gain the experience necessary to have an informed opinion. Patients in the position of Ms B, in his view, could only appreciate fully through experience.

63. Mr G clearly has great experience in the field of spinal injuries and in the process of rehabilitation. He accepted that Ms B had mental competence and his one reservation was his conclusion that she was unable to give informed consent, not because of a lack of capacity in general but her specific lack of knowledge and experience of exposure to a spinal rehabilitation unit and thereafter to readjustment to life in the community. Without that opportunity which might take up to two years to complete, Ms B did not have the requisite information to give informed consent. On that aspect of his evidence, I have the gravest doubts as to its legal validity and indeed its practicality. Even in issues of the utmost significance and gravity people, including patients, have to make decisions without experience of the consequences and his requirement is unrealistic.

**Dr I**

64. He is a consultant psychiatrist at a hospital unconnected with the Trust. He has extensive experience of patients with serious spinal injuries including tetraplegia. He visited Ms B in the ICU on the 8th February, 2002 and read extensively the documentation in this case. He spent three hours with Ms B. He reviewed aspects of his instructions with Ms B. He did not elicit any evidence of cognitive impairment. There was no evidence of persistent depression of mood. She gave a sense of strong vitality in equal measure to the frustration and pain that have led to being locked in her current state of disability. He wrote in his report

> "It appears difficult in this case to challenge Ms B's presumed capacity to consent to or refuse medical treatment. She appears

> to be rational in relation to her decision. The consequences of a decision to withdraw artificial ventilation are grave. In the light of the gravity, I understand that a greater level of competence is required in making the decision. I have found no evidence that psychiatric disorder interferes with her capacity to receive and retain information given to her, believe the information that has been provided or weigh the information in order to reach a decision.
>
> Of particular relevance here may be her attitude, in relation to information that suggests that she may have a different outcome if assisted further in a model spinal injuries system. She can understand that this is possible and believes that it is possible for some people. She believes that it may be possible for her but in her heart does not believe it is possible for her. Her deeply felt conviction cannot be considered irrational. Indeed, it may turn out to be true and suggestions to the contrary may turn out to be false. On the other hand, she has not actually been in care in such a system and although Ms B, clearly highly informed, cannot be considered to be 100% fully informed in view of the fact that she has not had the experience of being in such treatment. Being told about treatment is different to having experience of it."

65. Dr I identified a number of significant clinical factors which he said could be relevant and which he felt he ought to bring to the attention of the court. The situation in which Ms B was in an ICU in a general hospital might amount to a temporary factor so as to erode her capacity. The possibility was a significant one although he found it extremely difficult to determine whether it was more likely than unlikely. He felt that some aspects of the relationship between Ms B and those caring for her were strained.

66. Dr I formed the view in his assessment that she did not wish to close the last door but was prepared to contemplate further treatment/rehabilitation provided she was assured that she had the final say. In his oral evidence Dr I said that he had discussed the case on three occasions with Dr Sensky. It was Dr I's understanding that Ms B had not closed the last door and would go to a rehabilitation unit. He was surprised that she was significantly more positive and it was an important part of his opinion to the court. It was his experience that patients expressed a wish to die when they were breathless or in pain but once the acute state was treated the underlying psychiatric state improved and the patient changed his mind. The statement of Dr Sensky on the consistency of Ms B's wishes weakened his concern about possible ambivalence.

67. Another factor referred to by Dr I was that commonly patients who experienced serious illness might regress psychologically. He then referred to Ms B's childhood experiences. This was a very difficult area and in his report he was uncertain.

Psychological regression needed to be considered as a possibility rather than that it was present. It was a relevant consideration in deciding capacity. He set out a group of possible regressive factors which I do not propose to repeat since he said in cross-examination

> "I accept that the evidence I offered does not establish regression."

68. He felt a considerable degree of uncertainty about the possibility of a temporary factor eroding the capacity of Ms B in the present case. Being in the ICU might affect her ability to make decisions. The ICU was not geared to rehabilitation and the ethos was different from a rehabilitation unit, where patients rarely die. There was no mental incapacity. There were however broader social considerations. He did not state that Ms B did not have capacity but that there were relevant issues to be considered by the court. He felt acutely the dilemma of how rational was a man or woman, whether the legal concept of autonomy gave due weight to the emotional factors which drive reason, and the potential force of feelings for Ms B if she were treated in one hospital or in another, for instance in the ICU or a rehabilitation unit. He agreed that for a fresh start the patient must want it.

69. Dr I had discussed with Dr Sensky that it was more likely that considered judgment led Ms B to express her choice. He accepted that intellectually there was no inconsistency between Ms B's vitality and her wish to die, although emotionally it grieved him, which was not too strong a word. He concluded that he still held the view that it was difficult to challenge Ms B's capacity. There were some factual issues in dispute between Dr I and Ms B but in view of the overall picture, it is not necessary for me to adjudicate upon them.

70. In his view the principles of autonomy and beneficence would appear to be in conflict in this case.

> "If immediate priority is given to the patient's autonomy through acting according to her wishes, there is a risk of depriving her of potential benefits in the future."

71. Dr I gave very careful and thoughtful evidence in which he wrestled with the problems raised by Ms B in her request for the ventilator to be turned off. He recognised that she was competent although he looked throughout for reasons to demonstrate that she was not competent. Finally he accepted both in the telephone discussions with Dr Sensky and, in particular, in his oral evidence that none of his reservations in fact applied and that Ms B did not lack capacity to make decisions as to her medical care including the decision to have the ventilator turned off.

## Dr Sensky

72. The Official Solicitor instructed Dr Sensky, a consultant psychiatrist, who is Reader in Psychological Medicine at Imperial College of Science, Technology and Medicine. He has special experience of mental disorder and long experience in the assessment and management of psychiatric and psychological aspects of physical illness. He examined Ms B on the 5th February for an hour and a half and again for an hour on the 5th March. He has written three reports; read the other reports; discussed the issue with Dr I and gave the court a note of two telephone conversations with Dr I on the 2nd and 4th March 2002. He gave oral evidence to the court. The note of the telephone conversation included

> " Drs I and Sensky agree on the following
>
> a) Ms B can assimilate and understand information which has been given to her.
>
> b) She is capable of discussing information in detail with experts and lay people.
>
> c) She is capable of evaluating the information she has acquired and forming judgments on the basis of a process of weighing up the information she has acquired.
>
> d) During their respective interviews with Ms B, Drs I and Sensky elicited no evidence of a depressive illness, nor of any other specific mental state abnormalities which would point to the presence of a mental illness.
>
> The key difference in the opinions of Drs I and Sensky concerns the weight to be assigned to possible temporary factors on Ms B's capacity to express autonomous wishes."

73. Dr Sensky was very clear in his impressions of Ms B. In his evidence he said that there was no difference in the mental state of Ms B on either of the two occasions he interviewed her. She had a considerable degree of self-awareness and self-knowledge. She was an immensely impressive woman.

74. Dr Sensky was equally clear in his view as to Ms B's mental competence. He concluded she had the mental capacity to make decisions. In his overall judgment, Ms B was at the extreme end of competence, despite the limitations of her physical state and her environment in the ICU. She was likely to remain competent to make decisions for the foreseeable future. Dr Sensky's discussions with the clinical

psychologist who had seen Ms B regularly and frequently since Spring 2001, and with the senior nurse on the ICU and others who have cared for Ms B, confirmed his assessment that Ms B was not suffering from depression and was competent to reach the decision she had made. He excluded mental illness. He considered that she had a good understanding of her circumstances and had given a great deal of thought to her decision. She had gone to considerable lengths to find out the relevant information on her condition. She told him that she was a fighter by nature but said that

> "I cannot accept myself as disabled and dependent – it's too big a leap to make. The totality of dependence is intolerable."

75. Dr Sensky then addressed the concerns put forward by the Trust about perceived ambivalence in Ms B's views. He considered whether she had not yet closed the door on further treatment as was suggested by Dr I. If she had not closed the door that might be an indication of ambivalence. Ms B made it clear to him that the discussion on rehabilitation with Dr I only arose if her request to have the ventilator turned off was declined by the court. Dr Sensky did not find any evidence of ambivalence. Ms B's clinical psychologist confirmed to him that Ms B had been entirely consistent in her views about her treatment and her wish to have her treatment discontinued.

76. He also considered the opinion expressed by Mr G as to whether the environment in the ICU clouded her judgment. He did not consider that her judgment had been clouded either by her environment or by her professional carers. In the context of the decisions she wanted to make, despite expressing frustration, anger and criticism of some aspects of her management, she showed a good understanding of the position of the clinicians and was sensitive to them and to the nursing staff. He did not consider that her current views were unduly influenced by unresolved psychological problems in childhood and adolescence nor that there was any evidence of regression.

77. Dr Sensky then offered helpful insight into the difficulties with the way in which decisions about Ms B's treatment had been managed. He recognised the complexities involved in this case arising from the decision made by Ms B. He agreed that it was a highly unusual decision. He pointed out that it could be seen from the clinicians' witness statements how stressful and distressing the present situation is for all concerned. He agreed that in a decision of this magnitude the highest degree of scrutiny was required.

78. He pointed out that one thing which struck him forcibly was that the clinicians started from the decision made by Ms B, and not from the assessment of her competence. They looked too much at the decision, which was contrary to their advice and which they would not endorse, and not enough at the surrounding circumstances. The clinicians were not able to accept her views and deal with them. It was a fundamental

principle that one should start with the individual's capacity to make decisions and values. There may have been some confusion over her values compared with other people's, and it was important to focus on the individual and respect that individual's values. The weight which an individual chooses to give competing factors is an essential part of the decision-making process. A key issue in this case was the weighing up by Ms B of artificial ventilation and the stopping of ventilation and almost inevitable death. She valued the ventilator and her handicap as worse than being dead. Her decision was made against the advice offered and was not understood. Subjective values have to be taken into account. If at an earlier stage there had been an acknowledgement of a clash of values it might possibly have led to a different approach to management of the case.

79. Dr Sensky then offered some helpful observations on the proper management of these inevitably difficult cases. He recommended that the first step should be to recognise where the problem lay and the difference in values. It was a very complex decision with a potentially devastating outcome for clinicians. The second step was to get someone from outside, not in the first instance a lawyer, to help define the differences and to draw boundaries round the decisions to be taken. It was important that the patient came into contact with the outsider and the outsider should negotiate his/her involvement in the first place with the patient. It should be seen as a joint referral. When the impasse was identified, one should ask whether this is a problem of difference of values, or alternatively one of insufficient knowledge and understanding by the patient. If it were a case of a lack of information, the clinicians would manage it differently. He accepted that the level of physical disability might have an effect on capacity, as might the level of anger or inconsistent statements which should be looked at with great care.

80. The circumstances of Ms B illustrate the conundrum and how difficult ethically and personally it is for doctors serving people who only remain alive with the help of medical technology. In palliative care this option often arises and is not unfamiliar but in the setting of the ICU this is unusual. The principle is to have appropriate respect for values and recognise the patient's equal right to autonomy.

81. Dr Sensky referred to an article titled "Autonomy and the Subjective Character of Experience" (Journal of Applied Philosophy, vol. 17, no. 1, 2000), written by Dr Kim Atkins, a member of the Department of Philosophy at the University of Tasmania. I found this article helpful in the context of the present case and consider it would be useful to include some passages from it in this judgment.

82. Dr Atkins discussed the value of autonomy

> "If we accept that the subjective character of experience is irreducible and that it is grounded in the particularity of our

> points of view, then we are bound to realise that our respect for each other's differences and autonomy embodies a respect for the particularity of each other's points of view. Respect for autonomy is at the same time recognition of the irreducible differences that separate us as subjects.
>
> … While we can imagine, we cannot know objectively 'what it is like to be' another person, no matter how many facts we are in possession of…"

83. Dr Atkins said of illness,

> "…the more extreme the experience of illness, the more profound are the implications of this view for patient autonomy, because of the increasing difficulty for carers to raise the spectre of the subjective character of very unpleasant experiences. …"
>
> "Making way for the subjective character of experience is *not* achieved by offering up more facts for the person to 'face', it is achieved by allowing a place for the expression of a person's perspective on the nature of their illness and the treatment they are being offered. …"
>
> "We might want to criticise the practice of denying oneself life-saving treatment on some other grounds, for example, because of its effects on those the dying person expects to care for her, but it simply misses the point to criticise the practice on the grounds of insufficient objectivity." …
>
> "However disturbing it is to see someone, especially one's loved one, on something like [a ventilator], it is essential that one tries to imagine what it is like to be *that particular* person on [a ventilator] if one is to attempt to act from respect for *that person's* autonomy. The difficulty here lies not in becoming *more* objective, but in being appropriately subjective…. I need to imagine not just what it would be like to *me* to be on [a ventilator], but what it would be like for [Ms B]." …
>
> "Insisting that a decision be made from a fully objective perspective can only produce a decision that is further from the patient's own point of view, not closer to it."

84. I found Dr Sensky to be a most impressive witness. Dr I did not in any material particular really disagree with any of his reports. I accept unreservedly Dr Sensky's

assessment of the mental capacity of Ms B. I am also very grateful to him for wise advice for the future where an intractable, painful and distressing situation such as the present might arise. I have set out his evidence in some detail since, in my judgment, it may be of assistance for clinicians in the future.

85. I read the report of Professor B, a professor of Intensive Care Medicine from a hospital unconnected with the Trust. Professor B was not called to give oral evidence, but from his reading of the statements and clinical records he considered that there was no doubt that Ms B was now mentally competent. He understood why the clinicians were not prepared to turn off the ventilator and that it was clear that close relationships had been built up between the patient and the nurses and doctors. In his view the only option was to arrange for the patient to be transferred to a hospital which would be willing to grant the patient her wish. It would probably be an unprecedented event, at least in the United Kingdom and would have to be handled with the greatest delicacy and tact. He had discussed the situation with the senior medical, nursing and management staff at his hospital and they agreed that he should offer Ms B a bed at that hospital on the basis that he and his team would carry out Ms B’s wishes in respect of her future medical care.

## Submissions

86. Mr Havers submitted that the evidence conclusively proved that Ms B had the requisite mental capacity to make her own decision about her future medical care, and in particular, to decide whether artificial ventilation should be withdrawn. Mr Havers also submitted that, from the 8th August 2001 Ms B had been managed by the Hospital on that basis. The doctors had however been reluctant to accede to her wish to have the ventilation withdrawn. The clear advice of the solicitors to the Trust as to mental capacity in their letter of the 5th April 2001 had been ignored and the Hospital continued to treat her with artificial ventilation and to explore other alternatives which were unacceptable to Ms B. The clinicians at the Hospital were unwilling to accede to Ms B’s request and the Trust failed altogether to take the key step, which should have been taken at the outset, namely to find another doctor prepared to carry out the wishes of Ms B for over five months. Accordingly Mr Havers submitted that I should find that the Claimant had been treated unlawfully since August 2001 and that I should make a nominal award of damages in order for that situation to be recognised.

87. Mr Francis sought to convince me that Ms B did not have legal capacity in and from August nor did she have it now, despite the conclusions of the treating clinicians. He relied upon the evidence of Mr G and Dr I. He argued that if there was the possibility that the patient did not have capacity to decide whether to accept or refuse medical treatment, it was lawful for the doctors to continue treating the patient until the issue was resolved and the doctors were satisfied about mental competence. He submitted that there were temporary factors which in this case eroded Ms B’s ability to make this crucial decision. He adverted to the effect upon Ms B of the gravity of her physical disability and her reaction to being totally dependent upon others, the effect of the environment of the ICU, her relationship with the treating doctors and other carers,

her anger at her treatment, and possible regression prompted by childhood experiences. He relied upon her refusal to consider rehabilitation. He suggested that she had been ambivalent in her intention to have treatment withdrawn, for example the agreement to the bronchoscopies which she could have refused. He accepted that it was an extremely unusual case and it was necessary to examine very carefully the reasons given by Ms B and the assertion that she had capacity.

88. Mr Jackson, as Advocate to the Court, supported the submissions of Mr Havers as to mental capacity. He reminded me that the question of the best interests of the patient did not arise in this case. She was competent now and on the evidence would be competent for the foreseeable future. The finding of mental capacity would leave the patient, not with a past decision but with a future choice which she could consider freely when she was relieved of the burdens of litigation. He recommended a number of steps which the Trust might have taken and which might be helpful to consider for the future. They are very helpful and I consider them below. On behalf of the Official Solicitor, he made the very helpful suggestion that where a Trust finds itself in a serious dilemma it should not hesitate to approach the court. But in the first instance, if such a step were to be contemplated, he referred to the Official Solicitor’s Practice Note [2001] 2 FLR 158 and said that the Official Solicitor was available to give advice if asked.

## Conclusion on mental capacity

89. As I have already said Ms B was a most impressive witness. I therefore considered with especial care the evidence of the two psychiatrists and the submissions of Mr Francis for the Trust. I start with the presumption that Ms B has mental capacity. That presumption was displaced between April and August 2001 in the light of the assessments by Dr E and Dr L, which have not been challenged in this court. Dr RG in August assessed her as mentally competent and the Hospital thereafter treated her as such. Nevertheless, Mr Francis has argued that it is legal capacity which I must consider not the assessment of the mental capacity provided by the doctors. That may be so, but, unless it is an exceptional case, the judicial approach to mental capacity must be largely dependent upon the assessments of the medical profession whose task it is on a regular basis to assess the competence of the patient to consent or refuse the medical/surgical treatment recommended to the patient. If, as in the present case, two experienced and distinguished consultant psychiatrists give evidence that Ms B has the mental capacity to make decisions, even grave decisions about her future medical treatment, that is cogent evidence upon which I can and should rely. That evidence supports and reinforces the assessment of Ms B’s competence in August 2001. No psychiatrist has suggested since August that Ms B is not competent.

90. Mr Francis has pointed to a number of temporary factors which might affect Ms B’s competence or erode her capacity: possible evidence of psychological regression; the effect of her grave physical disability; the absence of her experience of rehabilitation which was thought likely to be a positive experience; and the effect of her

environment in the ICU. Mr Francis also points to concern about Ms B's history of ambivalence about ventilation and her consent to bronchoscopies.

91. It is important to note from the outset, as Dr Sensky properly emphasised in his evidence to the court, the importance of avoiding generalisations about the possibilities for patients in Ms B's position for capacity to be diminished by one or a number of temporary factors. Rather, the court's task in the instant case is to determine whether *in fact* Ms B's capacity is affected by any of the factors identified by the Trust.

92. I reject any suggestion that Ms B's capacity has been impaired by the advent of psychological regression. There is no evidence to support it. I do not consider that Ms B has been ambivalent in her determination to choose her medical treatment and in her wish to cease to have artificial ventilation. She did look at the alternatives and went down the path of rehabilitation when she was deemed incapable of making her own decision. As soon as she was deemed capable she made it clear that she did not want to go to a spinal rehabilitation unit and turned down the opportunity of a place in October last year. Her relief at not having to say goodbye to her family and friends in April is entirely explicable on two grounds. First, it must not be forgotten that she was deemed not competent at that time so it would be unjust of me to place great weight on her emotions. Second, if, contrary to the psychiatric assessment, she was competent, her explanation of relief in not undergoing painful and distressing final goodbyes to those she loves, does not seem to me to be incompatible with her long term objective of cessation of artificial ventilation. Equally there is no incompatability in consenting to the bronchoscopies, refusal of which she felt would involve pain and discomfort, which understandably she did not wish to undergo.

93. Mr G's evidence to the effect that one must experience the advantages of rehabilitation is probably excellent advice for the vast majority of paraplegic and tetraplegic patients. His view that not to have experienced rehabilitation means that the patient lacks informed consent cannot be the basis for the legal concept of mental capacity. If Mr G were correct, the absence of experience in the spinal rehabilitation clinic would deny Ms B or any other similar patient the right to choose whether or not to go to one. It is not possible to experience before choosing in many medical situations. That is not the state of the law nor, I assume, would the medical profession accept it for many fundamental and practical reasons.

94. One must allow for those as severely disabled as Ms B, for some of whom life in that condition may be worse than death. It is a question of values and, as Dr Sensky and Dr Atkins have pointed out, we have to try inadequately to put ourselves into the position of the gravely disabled person and respect the subjective character of experience. Unless the gravity of the illness has affected the patient's capacity, a seriously disabled patient has the same rights as the fit person to respect for personal autonomy. There is a serious danger, exemplified in this case, of a benevolent paternalism which

does not embrace recognition of the personal autonomy of the severely disabled patient. I do not consider that either the lack of experience in a spinal rehabilitation unit and thereafter in the community or the unusual situation of being in an ICU for a year has had the effect of eroding Ms B's mental capacity to any degree whatsoever.

95. I am therefore entirely satisfied that Ms B is competent to make all relevant decisions about her medical treatment including the decision whether to seek to withraw from artificial ventilation. Her mental competence is commensurate with the gravity of the decision she may wish to make. I find that she has had the mental capacity to make such decisions since the 8th August 2001 and that she will remain competent to make such decisions for the foreseeable future. I should however like to underline the wise submission made to me by Mr Jackson that my decision leaves Ms B with a future choice which she can consider freely now that she will be relieved of the burdens of litigation. She is not bound by her past decision and when she goes to the hospital prepared to accept her, she has the right to reflect on what she may wish to do with her life. I would like to add how impressed I am with her as a person, with the great courage, strength of will and determination she has shown in the last year, with her sense of humour, and her understanding of the dilemma she has posed to the Hospital. She is clearly a splendid person and it is tragic that someone of her ability has been struck down so cruelly. I hope she will forgive me for saying, diffidently, that if she did reconsider her decision, she would have a lot to offer the community at large.

### Remedies

96. In the light of my decision that the Claimant has mental capacity and has had such capacity since August 2001 I shall be prepared to grant the appropriate declarations after discussions with Counsel. I also find that the Claimant has been treated unlawfully by the Trust since August.

97. Throughout the sad developments of this case, all those looking after Ms B have cared for her to the highest standards of medical competence and with devotion. They deserve the highest praise. Ironically this excellent care has to some extent contributed to the difficulties for the Hospital. Ms B has been treated throughout in the ICU in which the medical and nursing team are dedicated to saving and preserving life, sometimes in adverse medical situations. As Dr C said, they are trained to save life. The request from Ms B, which would have been understood in a palliative care situation, appears to have been outside the experience of the ICU in relation to a mentally competent patient. It was seen by some as killing the patient or assisting the patient to die and ethically unacceptable. The solicitors to the Trust, Capsticks, wrote an excellent letter in April which set out with admirable clarity the legal position. As a result of the assessment of Ms B by Dr L and Dr E, the Trust did not have to reconsider the situation until August. At that time it would appear that the letter was not reread. The solicitors were not asked to advise further and the Trust over a period of seven to eight months went down a number of ineffective paths.

98. One route was the proposed one-way weaning process. Ms B was, in my view, placed in an impossible position by the treating clinicians who could not contemplate turning off the ventilator. If they had stopped to consider the likelihood of her being able to breathe unaided they presumably would have endorsed the possibility of success at not greater than 1%. In which case, the one-way weaning process was inevitably going to fail and she would die over three weeks and not in a few hours. I have to say, with some sadness, that the one-way weaning process appears to have been designed to help the treating clinicians and the other carers and not in any way designed to help Ms B. If the one-way weaning process were to be carried out as suggested by the doctors there would be a risk that she would die in discomfort and possibly in pain, even though that is not what they intended. It was obviously, to anyone looking at it from outside the hospital, an unrealistic and unhelpful programme. It was nonetheless supported by the Hospital and by the Trust. No-one stood back, as the solicitors undoubtedly would have done, had they been asked, and considered in an objective way the best way to go forward. The clinicians had clearly become emotionally involved. That situation was entirely understandable. They had with the nursing staff kept Ms B alive and looked after her in every respect including her most intimate requirements. Obviously a relationship built up and it was, in my view, unjust to the team in the ICU that the burden of decision and responsibility for Ms B largely remained in their hands. Although the issue of capacity may be a grey area, it is one capable of resolution by one means or another. The Trust had a duty to do something effective to resolve the dilemma and to do so with some degree of urgency for the sake of all concerned. This they consistently failed to do up to the hearing of the case in court. It fell to Ms B to initiate proceedings to get the issue resolved.

99. It is important to draw a careful distinction between the duties of the dedicated team in the ICU of the Hospital caring for Ms B and the Trust responsible for the working of the Hospital. In my view, the latter should have taken steps to deal with the issue. The failure to do so has led me to the conclusion that I should mark my finding that the Claimant has been treated unlawfully by the NHS Hospital Trust by a small award of damages. I shall not decide the amount until Mr Francis has had an opportunity to make representations if he wishes to do so.

## Guidance

100. Guidance has already been given by the Court of Appeal in *St George's Healthcare NHS Trust v S* [1999] Fam 26 at page 63 in the Guidelines at page 758 et seq. The circumstances of the present case are however very different from the facts of that case. It might therefore be helpful if I restate some basic principles and offer additional guidelines in case a situation similar to the present should arise again.

i) There is a presumption that a patient has the mental capacity to make decisions whether to consent to or refuse medical or surgical treatment offered to him/her.

ii) If mental capacity is not in issue and the patient, having been given the relevant information and offered the available options, chooses to refuse the treatment, that decision has to be respected by the doctors. Considerations that the best interests of the patient would indicate that the decision should be to consent to treatment are irrelevant.

iii) If there is concern or doubt about the mental capacity of the patient, that doubt should be resolved as soon as possible, by doctors within the hospital or NHS Trust or by other normal medical procedures.

iv) In the meantime, while the question of capacity is being resolved, the patient must, of course, be cared for in accordance with the judgment of the doctors as to the patient's best interests.

v) If there are difficulties in deciding whether the patient has sufficient mental capacity, particularly if the refusal may have grave consequences for the patient, it is most important that those considering the issue should not confuse the question of mental capacity with the nature of the decision made by the patient, however grave the consequences. The view of the patient may reflect a difference in values rather than an absence of competence and the assessment of capacity should be approached with this firmly in mind. The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment in answering the primary question whether the patient has the mental capacity to make the decision.

vi) In the rare case where disagreement still exists about competence, it is of the utmost importance that the patient is fully informed of the steps being taken and made a part of the process. If the option of enlisting independent outside expertise is being considered, the doctor should discuss this with the patient so that any referral to a doctor outside the hospital would be, if possible, on a joint basis with the aim of helping both sides to resolve the disagreement. It may be crucial to the prospects of a good outcome that the patient is involved before the referral is made and feels equally engaged in the process.

vii) If the hospital is faced with a dilemma which the doctors do not know how to resolve, it must be recognised and further steps taken as a matter of priority. Those in charge must not allow a situation of deadlock or drift to occur.

viii) If there is no disagreement about competence but the doctors are for any reason unable to carry out the wishes of the patient, their duty is to find other doctors who will do so.

ix) If all appropriate steps to seek independent assistance from medical experts outside the hospital have failed, the NHS Hospital Trust should not hesitate to make an application to the High Court or seek the advice of the Official Solicitor.

x) The treating clinicians and the hospital should always have in mind that a seriously physically disabled patient who is mentally competent has the same right to personal autonomy and to make decisions as any other person with mental capacity.

101. All those reading this judgment must be careful to recognise the importance of complying with the publicity injunction set out at the beginning of this judgment.