Neutral Citation Number: [2014] EWCOP 49

Case No: COP 11341264

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 27/11/2014

Before :

THE HONOURABLE MR JUSTICE BAKER

- -

IN THE MATTER OF THE MENTAL CAPACITY ACT 2005
AND IN THE MATTER OF THE SENIOR COURTS ACT 2005
AND IN THE MATTER OF AB

Between :

GLOUCESTERSHIRE CLINICAL COMMISSIONING GROUP	**Applicant**
- and -	
AB (1) (by his litigation friend, the Official Solicitor)	**Respondents**
CD (2)	

- -
- -

Fiona Paterson (instructed by **Bevan Brittan LLP**) for the **Applicant**
Michael Horne (instructed by **the Official Solicitor**) for the **First Respondent by his litigation friend the Official Solicitor**
Vikram Sachdeva (instructed by **Irwin Mitchell LLP**) for the **Second Respondent**

Hearing date: 20th November 2014

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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.

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THE HONOURABLE MR JUSTICE BAKER

IMPORTANT NOTICE

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment no person other than the advocates or the solicitors instructing them and other persons named in this version of the judgment may be identified by name or location and that in particular the anonymity of the 1st Respondent and members of his family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

The Honourable Mr Justice Baker :

Introduction

1. On 16th October 2005, a 55-year-old man, hereafter referred to as "AB", suffered a serious cardiac arrest while on holiday in France. Three days later he suffered a further collapse from which he never regained consciousness. For the last nine years he has been in hospital and subsequently in a residential home receiving artificial nutrition and hydration. It is not disputed that he lacks capacity to make any decisions, including as to his future care and treatment. His local health provider, now the Gloucestershire Clinical Commissioning Group ("the CCG") has applied for a declaration that it is in AB's best interests for artificial nutrition and hydration to be withdrawn. The respondents to the application are AB himself, represented by the Official Solicitor as his litigation friend, and his nearest relative, a cousin, who is the second respondent. The application was eventually listed before me for hearing in November 2014. Ultimately, all parties agreed that the declaration should be made and at the conclusion of the hearing, I indicated that I would make the declaration as sought by the CCG, together with ancillary and supplemental orders and directions. This judgment sets out the reasons for my decision.

Background

2. Prior to his collapse in 2005, AB had worked as a carpenter. He was unmarried with no children and apparently lived alone. His parents are deceased and the second respondent is his nearest relative. AB had an active life, enjoying fishing and, when he was younger, playing rugby. His cousin describes him as being very strong minded and spontaneous. His medical records show that he had been diagnosed with type II diabetes and hypertension in the course of 2005. The French hospital notes also suggest that he suffered from hypercholesterolaemia and obesity.

3. When in France on 16th October 2005, AB experienced severe chest pain and was admitted to hospital where he underwent a coronary angiogram and a procedure for the insertion of a stent into his left circumflex artery. Early in the morning of 19th October 2005, he had a cardiac arrest, apparently due to the failure of the stent. Normal cardiopulmonary resuscitation procedures were followed. The records show that he was in asystole with no spontaneous cardiac contraction for a period of 35 minutes. He was comatose with fixed dilated pupils and subjected to sedation. An EEG carried out on 23rd October showed severe changes compatible with anoxic brain damage. The following day, he underwent a CT brain scan which showed evidence of diffuse cerebral oedema with focal left parietal cortical hypodense areas suggestive of local ischaemic cerebral infarction. Professor Wade, whose evidence I consider in more detail below, informed the court that the presence of such evidence on the CT scan at so early a stage after collapse indicated the seriousness of the brain damage.

4. On 4th November 2005, AB was repatriated to the intensive care unit at his local hospital in England. He remained deeply unconscious with a Glasgow coma scale score of 3/15, the lowest possible. Further tests confirmed the presence of extensive brain damage. On 8th November 2005 he underwent a tracheostomy and was discharged onto the neurology ward three days later. His coma scale score remained low. On 21st December 2005, he underwent a procedure for the insertion of a PEG tube. In March 2006, he was started on sensory stimulation. On 22nd August 2006, he was moved into a residential home, and three weeks later moved to his current home where he has remained ever since. From time to time he has been admitted to hospital for interventions in relation to the PEG tube and his tracheostomy. At all other times, he has remained in his residential home. All the evidence shows that the quality of care he has received there has been high.

Diagnosis

5. The evidence demonstrates conclusively that AB is in a vegetative state and in all probability he has been in that state since October 2005.

6. The Royal College of Physicians working party report entitled "Prolonged disorders of consciousness – national clinical guidelines", published in 2013, provides definitions of the prolonged disorders of consciousness – coma, vegetative state, and minimally conscious state. For the purposes of this judgment, it is only necessary to consider the latter two conditions. Vegetative state ("VS") is defined as "a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours." VS is said to be "characterised by complete absence of behavioural evidence for self- or environmental awareness". Minimally conscious state ("MCS") is defined as "a state of severely altered consciousness in which minimal but clearly discernable behavioural evidence of self- or environmental awareness is demonstrated". MCS is said to be "characterised by inconsistent but reproducible responses above the level of spontaneous or reflexive behaviour, which indicates some degree of interaction with their surroundings".

7. The evidence consists primarily of the results of two formal assessments using an assessment tool known as the Sensory Modality Assessment and Rehabilitation Technique ("SMART") and the professional opinion of Professor Derick Wade, who is a Consultant in Neurological Rehabilitation at the Oxford Centre for Enablement

and Professor of Neurological Rehabilitation in the University Department of Clinical Neurology at the John Radcliffe Hospital in Oxford. Professor Wade is recognised as a leading expert in the diagnosis assessment and management of adult patients with neurological disability arising from any cause, the organisation of and research into rehabilitation treatments and the diagnosis of the permanent vegetative state.

8. SMART is a standardised assessment for VS and MCS patients. The assessor's report in this case describes it as having been "designed to elicit behavioural responses to a comprehensive range of stimuli, enabling the accredited SMART assessor to identify the type of quality of patient's behaviours and sensory responses. The aim of SMART is to assess patients' level of sensory response, motor function, information processing and to *identify evidence of awareness*." SMART is recommended by the Royal College of Physicians working party as the tool of choice in the assessment of VS patients.

9. The assessment process is described in the report prepared in this case as follows:

> "SMART consists of both a formal and informal component. The formal component requires assessment by the SMART accredited assessor over ten sessions within a 3-week period, with both the SMART behavioural observation assessment and SMART sensory assessment. This high frequency of assessments provides quantitative measure of change over time and identification and evidence of awareness and meaningful responses.
>
> SMART behavioural observation assessment comprises of ten times ten-minute formal observations of patients' behaviours at rest. This assessment is followed by SMART sensory assessment, which consists of visual, auditory, tactile, olfactory and gustatory, motor function, communication function and wakefulness-arousal modalities. Each modality is scored on a five-point hierarchical scale and measures the quality of the response from SMART level 1 = no response, 2 = reflex, 3 = withdrawal, 4 = localising, 5 = differentiating response. A consistent meaningful response at SMART level 5 (on five or more consecutive sessions) in any one of the sensory, motor or communication modalities is indicative of evidence of awareness.
>
> The informal component of SMART is completed by family friends and/or carers and consists of the communication lifestyle history questionnaire and SMART Informs. The [questionnaire] provides the SMART assessor with an overview of the patient's interests, likes and dislikes. SMART Informs record the patient's behaviours during day to day activity and enables the SMART assessor to identify a potential meaningful behaviours and ensure that SMART treatment is customised to optimise positive response.

> Following the assessment period, a structured eight-week SMART treatment programme is designed to optimise the patient's future potential for both communication and functional activity. A follow up SMART reassessment is compared to the baseline assessment and future requirement identified."

10. It is believed that a SMART assessment of AB was carried out some time before 2012, but curiously no record of this assessment survives. Since then, there have been two SMART assessments, each carried out by trained assessors, each of whom reached the clear conclusion that AB was in the VS. In both assessments, his behaviours were either reflexive or spontaneous, with no evidence of any purposeful behaviour. He demonstrated no awareness of, or meaningful responses to, the visual, auditory, tactile, olfactory, gustatory, or motor stimuli presented during the SMART assessment periods. There was no evidence of communication. A similar picture emerged as a result of analysis of the questionnaire and "SMART Informs" data provided by care staff.

11. Following the second SMART assessment, the assessor suggested a simple sensory programme be carried out. This was duly done in Summer 2014 by a specialist occupational therapist and accredited SMART assessor. No improvement in AB's level of awareness was noted during or after the programme when the assessor carried out a further detailed SMART assessment, and the assessor confirmed that AB was in the VS. This assessment was confirmed by the observations of staff in the residential home.

12. Professor Wade has prepared two reports and attended court to give oral evidence. On the basis of the SMART assessment, and his own examination, he concludes that AB is in the VS, attributable to the extensive hypoxic brain damage sustained in 2005. He felt in 2013 that there was no clinical doubt about this diagnosis and no need for any further clinical assessment. In his most recent report, in November 2014, completed after the final SMART reassessment, he confirmed his diagnosis. He noted isolated reports of observations of possible localised responses, but did not consider these undermined the overall conclusion of the SMART assessment. Like many people in VS, AB shows occasional spontaneous movement, but the theory underpinning the SMART assessment is that such movements are only significant if repeated and there is no evidence of repeated movements or responses discernible in this case. Professor Wade considered the range of stimuli used in the SMART assessment in this case to be appropriate and felt that further analysis was unwarranted. He did not recommend the use of other, technologically-based procedures, which have been devised for the purposes of research and are not as yet in use for the purposes of diagnosis.

13. Professor Wade therefore concludes that AB is in the VS. The fact that he has, in all probability, been in this condition for over nine years, reduces the scope for any ambiguity. Over this time, there has been hardly any observation to suggest that he was in any way aware. In oral evidence, Professor Wade was shown a test result carried out in 2007, using another tool commonly used for the diagnosis of consciousness (the Wessex Head Injury Matrix – "WHIM") in which there was one isolated score suggesting that AB was in a minimally conscious state. Professor Wade was very sceptical about attaching any weight to this result. The raw data on which it was based was unavailable, the qualifications of the assessor were unclear, and in any

event the theoretical basis for the WHIM, as for SMART, is postulated on analysis of behaviour over time, as oppose to isolated observations.

14. In oral evidence, Professor Wade stated that, compared to other cases in which he had advised, the diagnosis in this case is very clear. He had no hesitation in concluding that AB is in the VS.

15. I accept the clear evidence provided by the SMART assessor and Professor Wade. I conclude that AB is certainly now in the VS, and, in all probability, that he has been in that state for nine years. I conclude that this state is permanent and that there is no prospect of any recovery.

16. It follows that AB lacks the capacity to make any decisions concerning his care and treatment, including as to artificial nutrition and hydration, because he is unable to make any decisions for himself as a result of an impairment of, and/or disturbance in, the function of his mind or brain, within the meaning of sections 2 and 3 of the Mental Capacity Act 2005.

The Law

17. I have set out the legal principles to be applied in these cases at some length in my earlier decision in *W v M and Others* [2011] EWHC 2443 (Fam) [2012] COPLR 222 at paras 57 – 96. It is unnecessary here to recite those principles, which are well established and can be summarised as follows:

i) "An act done, or a decision made, under the Mental Capacity Act 2005 for or on behalf of a person who lacks capacity must be done, or made, in his best interests" Section 1 (5) of the Act.

ii) In determining what is in the best interests of an incapacitated adult, the court must apply the relevant provisions of section 4 of the Act in particular subsections (1) to (7):

> "(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of (a) the 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 what might be in his best interests.
>
> (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 the capacity in relation to the mater 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 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 by the court."

iii) Where a person is unable to consent to medical treatment, it is lawful to provide the patient with treatment if it is necessary and in his best interests: *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

iii) The focus is not on whether it is in P's best interests to withhold treatment but rather on whether it is in his best interests to give or continue the treatment: *Aintree University Hospitals NHS Foundation Trust v James* [2014] 1 AC 591 at paras 18-22 by Baroness Hale of Richmond.

iv) In making a decision concerning life sustaining treatment, the court must have regard to the relevant articles of the European Convention for the Protection of Human Rights and Fundamental Freedoms, in particular Articles 2 and 8.

v) "Article 2…imposes a positive obligation to give life-sustaining treatment in circumstances where, according to responsible medical opinion, such treatment is in the best interests of the patient but does not impose an absolute obligation to treat if such treatment would be

futile": per Butler-Sloss P in *NHS Trust A v M* [2001] Fam 348 at para 36.

vi) Article 8 encompasses, inter alia, considerations of a patient's personal autonomy and quality of life. In *Pretty v UK* [2002] 35 EHRR 1 at para 65, the European Court of Human Rights observed:

> "The very essence of the Convention is respect for human dignity and human freedom. Without in anyway negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advance physical or mental decrepitude which conflicts with strongly held ideas of self and personal identity."

vii) When assessing best interests, it would normally be appropriate to adopt the "balance-sheet" approach recommended by the Court of Appeal in *Re A (Male Sterilisation)* [2000] 1 FLR 549 at page 560 Thorpe LJ.

viii) However, in cases of a VS, the balance sheet approach is not normally appropriate because all the factors that are relevant normally fall on one side of the scale.

ix) The fundamental principle derived from the case of *Airedale NHS Trust v Bland* [1993] AC 789 is as identified by Lord Goff of Chieveley at page 869:

> "Here the condition of the patient, who is totally unconscious and in whose condition there is no prospect of any improvement, is such that life-prolonging treatment is properly to be regarded as being in medical terms useless…for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement of his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means."

Discussion and Conclusion

18. All parties are now agreed that AB's life is futile, in the sense of that word used by Lord Goff in the ***Bland*** case. The Official Solicitor very properly withheld his consent until Professor Wade had answered questions in oral evidence, but thereafter gave his agreement.

19. AB has no awareness. He merely exists. There is no prospect of recovery. This court accepts the fundamental importance of the sanctity of life, but, as Butler-Sloss P noted in the passage cited above, that is not an absolute principle and does not impose an obligation to provide treatment where life is futile.

20. AB has not made any advance decision under section 24 of the Act or under any previous legal provision. His cousin states, however, that he would not wish to continue treatment in these circumstances. In her statement for these proceedings, she said:

> "I know that [AB] would not wish to be alive in this condition and if he could he would ask me why I was keeping him alive in this condition…AB would hate to know he was being looked after 24 hours a day. AB would never have imagined to be living in his condition; he would find it intolerable to be lying in a bed with no prospect of improvement or awareness. I am certain that in knowing AB he would want the life sustaining treatment to be withdrawn if he knew of his condition.

21. In all the circumstances, I unhesitatingly conclude that it is not in AB's best interests to continue to receive artificial nutrition and hydration and that it would be in his best interests for artificial nutrition and hydration to be withdrawn, provided this is carried out in an appropriate fashion by nursing staff trained in the provision of palliative care.

22. In his final report, Professor Wade makes a number of recommendations as to the management of the withdrawal of artificial nutrition and hydration and subsequent treatment – see paras 6.4 – 6.18 of his report – and I endorse those recommendations.

23. I therefore make the declaration sought by the CCG.