Neutral Citation Number: [2011] EWHC 2443 (Fam)

Case No: COP 1182483

IN THE COURT OF PROTECTON

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 28/09/2011

Before :

THE HON MR JUSTICE BAKER

- -

Between :

W (by her litigation friend, B)	**Applicant**
- and -	
M (by her litigation friend, the Official Solicitor)	**1st Respondent**
- and –	
S	**2nd Respondent**
- and -	
A NHS Primary Care Trust	**3rd Respondent**

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Vikram Sachdeva and Victoria Butler-Cole (instructed by **Irwin Mitchell**) for the **Applicant**
Caroline Harry Thomas QC and Katherine Apps (instructed by **the Official Solicitor**) for **M**
Bridget Dolan (instructed by **Beachcroft LLP**) for the **Primary Care Trust**
S was present for part of the hearing but not represented

Hearing dates: 18th to 22nd and 25th to 29th July and 1st August 2011

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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 HON MR JUSTICE BAKER

This judgment is being handed down in private on 28 September 2011. It consists of 76 pages and has been signed and dated by the judge. The judge hereby gives leave for it to be reported.

The judgment is being distributed on the strict understanding that in any report no person other than the advocates or the solicitors instructing them (and other persons identified by name in the judgment itself) may be identified by name or location and that in particular the anonymity of M, W, B and S and members of their family must be strictly preserved.

SUMMARY

1. On the morning of 17th February 2003, when she was supposed to be leaving for a skiing holiday, M, then aged forty-three, was found by her partner S in a drowsy and confused condition. She was taken to hospital where she soon fell into a coma. It was discovered that she had suffered viral encephalitis which left her with extensive and irreparable brain damage. Ever since, she has been wholly dependent on others for her care, and since April 2003 fed artificially via a gastrostomy tube.

2. When M emerged from the coma, the doctors diagnosed that she was in a vegetative state. After several years of exploring all options in the hope that she would recover consciousness, members of her family decided, with the support of the treating doctors, to apply for a court order authorising the withdrawal of artificial nutrition and hydration. On 16th January 2007, in accordance with the procedure then in force, an application was made to the Family Division under the inherent jurisdiction of the High Court seeking a declaration that M lacks capacity to make decisions as to future medical treatment (which has never been in dispute) and a further declaration that the doctors may lawfully discontinue and withhold all life-sustaining treatment including artificial nutrition and hydration.

3. In the course of subsequent investigations for the purposes of the application, however, it was discovered that M was in fact not in a vegetative state but rather in what is called a minimally conscious state. A patient in this condition is above the vegetative state and is aware to some extent of herself and her environment but does not have full consciousness. After extensive further investigation, however, M's family decided to proceed with the court application, which ultimately came before me in July 2011 sitting in the new Court of Protection, to which the jurisdiction to hear such applications had been transferred by the Mental Capacity Act 2005.

4. Any decision made under the Mental Capacity Act for a person who lacks capacity must be made in her best interests. The law requires the court to identify those factors which are relevant to the person's best interests and carry out a balancing exercise weighing up the factors on each side of the issue. This approach is well established in cases involving medical treatment. This is, however, the first time in this country that a court has been asked to authorise the withdrawal of artificial nutrition and hydration from a patient in a minimally conscious state.

5. The hearing before me lasted ten days. I heard evidence from B and S who spoke movingly about M and contrasted her previous life with her current circumstances. They told me about things that M had said before her collapse which, they maintain, demonstrated that she would not want to be kept alive in this condition. I also heard evidence from a number of members of the dedicated team of professional care staff, skills workers and physiotherapists who look after M in her present nursing home. They portrayed her life in much more positive terms that those used by members of her family. I heard evidence from Helen Gill-Thwaites, a specialist occupational therapist who has developed a widely-used and internationally-respected assessment technique known as the "SMART", and who applied that technique to M on two occasions to assist in the diagnosis of her level of consciousness. Finally, I heard from

two leading experts in neuro-rehabilitation – Mr. Derar Badwan and Professor Lynne Turner-Stokes – who expressed contrasting opinions on M's level of consciousness, and also on the ultimate question whether it is now in M's best interests for ANH to be withdrawn.

6. The case put forward on behalf of M's family is based substantially on what they say were, and still are, M's wishes and feelings. The law rightly requires the court to take into account M's wishes and feelings when determining her best interests. Importantly, however, M did not make any formal advance decision that she wanted artificial nutrition and hydration to be withdrawn in the circumstances that now exist. Had she done so, under the law that existed in 2003, the court would have abided by that advance decision. Under the new Mental Capacity Act, there is now a statutory procedure for making advance decisions, protected by stringent safeguards and formalities. If those safeguards and formalities are satisfied, the advance decision is binding. In this case, the various statements made by M prior to her illness in 2003 were informal, and not specifically addressed to the question I have to decide. Accordingly, whilst I take those statements into account, they are not binding and in all the circumstances I do not consider they carry substantial weight in my decision.

7. The factor which does carry substantial weight, in my judgment, is the preservation of life. Although not an absolute rule, the law regards the preservation of life as a fundamental principle. As another judge has said: "there is a very strong presumption in favour of taking all steps which will prolong life and, save in exceptional circumstances, or where the person is dying, the best interests of the patient will normally require such steps to be taken".

8. M does experience pain and discomfort, and her disability severely restricts what she can do. Having considered all the evidence, however, I find that she does have some positive experiences and importantly that there is a reasonable prospect that those experiences can be extended by a planned programme of increased stimulation.

9. Having weighed up all the relevant facts, I conclude that it is not in M's best interests for artificial nutrition and hydration to be withdrawn and I therefore refuse the application.

10. It is, however, agreed that the existing "Do Not Resuscitate" order should be continued. I conclude that other treatment decisions should be left to the clinicians to determine in consultation with M's family. I will in due course hear further submissions about the details of M's future care plan.

11. I realise that this decision will be a severe disappointment to members of M's family who have endured years of anguish during which they have demonstrated their deep devotion to M. I hope it would be of some comfort to the family that M will continue to be looked after in her current nursing home, which I have visited during the course of the hearing. All parties, including members of M's family, agree that the care given to M at the nursing home is of the highest standard. I urge everyone concerned with M – doctors, care staff, and her family – to work together to agree a revised care plan which gives her an opportunity of more positive experiences.

BACKGROUND

12. M was born on 12 September 1959 and is therefore now fifty-two years old. Until her illness, she had always lived in the same town in the north of England where other members of her family still reside. She has two siblings, a brother, some ten years older than she, and a sister, B, to whom she has always been very close. After their parents were divorced, M and B were looked after by their mother, W. When they left school, both M and B became hairdressers and worked together for a number of years before B left the salon to look after her two small children.

13. In 1982, when she was twenty-two years old, M met a man called S, who was some two years older, and they started their relationship which continues to this day. They lived together in the same town in a succession of properties, latterly in a house owned in their joint names. Although they never married, nor had any children, M and S were clearly in a very close, loving, stable and permanent relationship.

14. On 17 February 2003, the day before she was due to go on a skiing holiday with S, M went to bed early complaining of a headache. The following morning, S was surprised that M, contrary to her usual habit of rising early, was still in bed when he woke. She was drowsy and confused, and he therefore telephoned NHS Direct who ordered an ambulance to attend at the property. M was admitted to hospital where her condition quickly deteriorated so that within a short space of time she was in a coma. The doctors diagnosed that she had suffered from viral brain stem encephalitis, although no cause of the virus was ever identified. She remained in a coma for some weeks and although she recovered consciousness, it became apparent that she had suffered extensive, irreparable and devastating brain damage. Since April 2003, M has been fed and hydrated via a gastrostomy tube. She remains totally dependent on others for all aspects of her basic daily care. She is immobile and has limited head and trunk control. She is doubly incontinent. She has flexion contractures in the elbows, hips, knees and Achilles tendon. She is moved by hoist for all transfers.

15. In Autumn 2003, she was transferred to another hospital in the same town with a specialist rehabilitative unit. For some time she suffered from facial twitching and epilepsy, but these symptoms gradually decreased and had settled by 2006. She remained in that hospital for over four years. During that time there were many conversations between the doctors treating her and members of her family, principally S, B and W. From an early stage the consensus of medical opinion was that there was no realistic prospect that any improvement could be achieved in M’s condition. For some time, the family members, in particular S, fought hard to ensure that every possible attempt was made to identify processes of rehabilitation which might bring about some improvement. Despite these efforts, there was at that stage no discernable sign of any change. Dr W, the consultant in rehabilitation medicine at the hospital responsible for treating her, expressed the view that M had suffered irretrievable and severe brain damage, that she was unlikely to improve and that she had reached the stage where she should be cared for in the community with appropriate nursing support and help.

16. Once the family members had accepted the prognosis provided by the treating clinicians, they gradually came to the view that they did not think it was in M’s interests to be sustained alive by artificial means. The family and the NHS Hospital Trust therefore instructed Professor Keith Andrews, then Consultant Physician and Director of the Institute of Neuro-palliative Rehabilitation, to carry out an assessment, first, as to M’s diagnosis and in particular whether or not she was in a permanent

vegetative state, and, secondly, as to whether it was appropriate to discontinue artificial nutrition and hydration. Professor Andrews reached the conclusion that M was clinically in the vegetative state and had been so for at least three years at the time of his report. Although members of staff at the hospital noted occasional responses, such observations were isolated and amounted to "inconsistent islands of function" which would still fit within the criteria of the vegetative state. In the view of Professor Andrews, further investigations would add nothing to the clinical knowledge already available regarding the extent of her brain damage. He formed the view that there was no clinical reason why life-sustaining treatment should not be discontinued.

17. Following Professor Andrews' report, the family decided to bring proceedings for declarations that it was not in M's best interest to be given life-sustaining medical treatment measures, including nutrition and hydration by artificial means ("ANH"), and further that such measures could lawfully be discontinued. As it pre-dated the implementation of the Mental Capacity Act 2005, and the introduction of the new Court of Protection, the application, dated 16 January 2007, was filed under the inherent jurisdiction of the High Court Family Division. On 23 January 2007, Sumner J made a declaration that M lacked capacity to conduct her own affairs, to litigate, and to make decisions regarding her medical treatment. Further directions were given, including an order appointing the Official Solicitor to act as litigation friend for M, and granting permission to him to instruct an expert witness.

18. Pursuant to this direction, the Official Solicitor instructed Mr Derar Badwan a former neurosurgeon and currently lead clinician in rehabilitation medicine at the University Hospital of Coventry and Warwickshire and consultant at the Royal Leamington Spa Rehabilitation Hospital. His first report in these proceedings is dated 10 April 2007. He noted that M's medical records appeared to disclose repeated occurrences in which she responded to command. He expressed the view that those responses, taken in isolation, would be of limited significance, but considered together they constituted what Mr Badwan described as "a repeated and reproducible, but inconsistent response to command". He concluded that, whilst there was some evidence that M would meet the accepted criteria for the diagnosis of vegetative state, there were doubts about the diagnosis that suggested it remained possible that she was in fact in a condition above the vegetative state generally known (since the publication of a research paper in the United States in 2002, as to which see below) as the "minimally conscious state".

19. Mr Badwan noted that there had been no structured assessment to establish her level of awareness. During the last fifteen years, a number of assessment techniques have been developed in several countries, including the "Sensory Modality Assessment and Rehabilitation Technique", generally known, and hereafter referred to, as "SMART", developed initially in this country by Helen Gill-Thwaites, an occupational therapist specialising in acquired brain injury. The SMART assessment is widely recognised here and abroad, and has been professionally validated as a method of diagnosing the level of awareness and consciousness in a patient with profound brain damage. Mr. Badwan recommended that M should undergo a SMART assessment in order to settle any doubts about the diagnosis. After discussion with Mr Badwan, Professor Andrews changed his mind. In a letter to solicitors acting for the family, after talking to Mr Badwan, Professor Andrews wrote that he and Mr Badwan, "both agreed that M

does not categorically fit into the diagnosis of the vegetative state". He endorsed the proposal that she should undergo SMART assessment.

20. All parties agreed that such an assessment should be carried out and a consent order endorsing that proposal was made on 1 May 2007. The SMART assessment was carried out by Miss Helen Gill-Thwaites herself over a three-week period in June 2007, and her findings and recommendations were set out in a report dated 28 June. Miss Gill-Thwaites found that M's responses were incompatible with the diagnosis of vegetative state but rather that, based on the results of the SMART assessments the likely diagnosis was of at least a minimally conscious state. Amongst the most striking observations made in the course of this SMART assessment was that M demonstrated a repeated ability to obey commands, notably when asked to press a buzzer switch. Miss Gill-Thwaites recommended that M undergo a specifically designed SMART treatment programme to explore whether her quality of life could be further developed and, in particular, whether she could be assisted to communicate.

21. Following her report, a joint report was prepared by Mr Badwan and Professor Andrews dated 3 July 2007. In the light of the SMART assessment, they advised that M was in a minimally conscious state, but added that there was a possibility that she was in fact at a higher level of function than she was at that time demonstrating. They supported the proposal that M undergo a special treatment programme prior to reassessment by Miss Gill-Thwaites. In a separate report dated at this time, Mr Badwan reiterated his view that M was not in a vegetative state but that rather her level of awareness was consistent with at least upper levels of minimally conscious state. He noted that for any person to be able to respond to a verbal command (1) she must hear such commands; (2) she must understand the contents of the command i.e be able to process the information and (3) be able to activate areas of the brain selectively in order to perform the act or command requested. He observed that the ability to obey a verbal command on repeated occasions is inconsistent with a diagnosis of vegetative state. He concluded that up to that point, she had not received appropriate rehabilitation and that it was not in her best interests to remain at her present hospital. Professor Andrews agreed. Having observed the DVD taken during the first couple of SMART assessment, he wrote a letter to the Official Solicitor noting specific responses which he considered of particular importance namely the obedience to command and in particular the test using the buzzer. About this, he observed: "she pressed the buzzer switch once and released on command. She did this on several occasions. It is of note that she released immediately whereas many severely brain-damaged people have difficulty in releasing". He reached this conclusion:

> "It is clear to me that M has a high[er] level of responses than previously identified. Because of the lack of consistency and the inability to use them, as yet, for communication purposes, this places her in the diagnostic category of minimally conscious state – but at a moderate level of MCS. I say moderate level to indicate that these are not simple responses but are indicating some sophistication in the response level… in summary, it is clear to me that she is NOT in the vegetative state. Moreover, she is making responses at a level that must raise the possibility that she will eventually be able to communicate. In view of this, it is my opinion that she requires the opportunity of access to a team

> very experienced in the assessment on management of people with this level of profound neurological disability."

22. Mr Badwan and Professor Andrews recommended that M be transferred to the Royal Neurological Hospital in Putney. This course was endorsed at a further court hearing on 11 July 2007. Accordingly M was transferred to the unit in Putney on 12 September of that year and remained there for five months. Unfortunately, she did not make the progress that the experts had hoped for. The discharge report following the admission to Putney recorded:

> "During the initial examination, it was quite apparent that M was not in a vegetative state by demonstrating the ability to respond purposefully to a simple command. She displayed marked hypersensitivity, as squeezed her eyes tightly shut most of the time. When her eyelids were held open, the pupils were both equal and reactive to light, the gaze was not divergent, nor was there any mystagmus noted. In fact, there was evidence of eye tracking and fair fixation of gaze. There were interspersed vocalisations, consisting with mostly of unintelligible groans, but not as a response to a painful or noxious stimulus."

However, the hospital was unable to make progress in M's rehabilitation. At the conclusion of her stay at Putney the unit concluded that

> "Despite showing islets of ability to respond to basic commands, and hence selected awareness of certain aspects of her external environment, M was not demonstrating a consistency of high level response which could be incorporated into function. Her responses remained non-functional".

They therefore concluded that no further therapeutic intervention was appropriate at that stage. However, it was advised that the occupational therapist at the Putney Hospital should provide interaction guidelines for M to be followed by those responsible for her daily care and treatment.

23. On 11 February 2008, on being discharged from the hospital in Putney, M returned to her home area in the north of England and was admitted to a care home where she remains. It is the unanimous view of everyone in this case, including family members, the Official Solicitor, and all experts, that the quality of care that M receives at her care home is of the highest standard, as was obvious to me when I visited M in the course of the hearing.

24. In January 2009, Professor Andrews retired and in his place, W's solicitors instructed Professor Lynne Turner-Stokes to carry out a further report on M's capacity and diagnosis and whether or not it would be still appropriate for the application for a declaration to withdraw artificial nutrition and hydration to proceed to a court hearing. Professor Turner-Stokes provided her first report on 12 July 2009. She agreed with the diagnosis that M was in a minimally conscious state but, in contrast with Mr Badwan, she concluded that M's state was at the lowest level within that category, in effect on the border of the vegetative state. She noted the reports which she received

from members of the staff in the care home as to signs of response in M, but concluded that M was variable in her level of responsiveness. Professor Turner-Stokes questioned the accuracy of some of the reports. She stated that she was unable to identify any aspect of M's life that gave her positive pleasure or satisfaction. On the contrary, Professor Turner-Stokes concluded that M had marked hypersensitivity and was experiencing a significant level of discomfort and, on occasions, pain. She confirmed that that there was no realistic possibility of recovery and concluded that, in her opinion, it would be appropriate to withdraw artificial nutrition and hydration to allow M to die in dignity.

25. Following this report, the family members decided to proceed with the application to the court. On 25 February 2010, at a direction hearing before Holman J, the proceedings were transferred to the new Court of Protection, which by that stage had come into existence following the implementation of the 2005 Act, and further directions were given, including a supplementary report from the independent expert instructed by the Official Solicitor, Mr Badwan. In his assessment carried out in May 2010, he recommended to staff at the care home that they should take M into the community as part of her care plan. In order to advance that proposal, a "best interests" meeting took place on 7 June 2010 attended by care staff, family members and the parties' legal representatives. It was the firm view of the family members, in particular S and B, that they did not support the recommendation that M be taken into the community to test her responsiveness. Their view was endorsed by a letter from Professor Turner-Stokes stating that she did not agree with Mr. Badwan's recommendation that M should be taken for trips or other stimulatory activities.

26. Mr Badwan then filed another report in which he documented information provided by the care staff setting out evidence of responsiveness demonstrated by M which he said was an essential part of the diagnosis of minimally conscious state. He concluded that M "has demonstrated several behaviours that are consistent with the diagnosis". As she had shown a number of behaviours, Dr Badwan concluded that he did not consider that she was near the border between minimally conscious state and vegetative state but, rather, at a higher level. He added in his view, her life expectancy was at least a further ten years. He assessed that "her present quality of life is reasonable and could be further improved taking into account recommendations made for future management". He recommended that, in order to improve her quality of life, she should be encouraged to watch television, listen to music and look at magazines. He reiterated the view that it would be to her advantage to be taken out of the nursing home.

27. There was then a short hiatus in the proceedings because of a further sad misfortune which befell the family. M's mother W, was found to be suffering from Alzheimer's disease. The discovery of her condition led her to withdraw as the claimant and this led to further extensive attempts to identify an appropriate person to take on the proceedings in her stead. It is unnecessary for me to recite the details of those steps. Suffice to say that it was eventually decided that W should continue as the claimant but acting via her own litigation friend, her daughter, (that is to say M's sister) B. At this point, it is appropriate to note that, as W's means are now above the level at which she would be entitled to public funding, her legal representatives are acting on a pro bono basis, as is Professor Turner-Stokes.

28. A further dispute then arose between the parties as to whether or not a further SMART assessment should be carried out, a course recommended by Professor Turner-Stokes. That lack of agreement led to a further directions hearing before me on 9 December 2010 at which I ordered that a best interests meeting should take place on 17 December to draw up a proposed care plan for M's care and management pending the final hearing and to reconsider whether M should be taken on outings and the question of a further SMART assessment. In the event that the parties were unable to agree on that course of management, I provided for a review hearing to be fixed in early January before me. The best interests meeting took place on the 7 December and was again attended by members of M's family, her care staff, and the parties' legal representatives. At that meeting it was agreed that M would be taken out into the local community for short visits in the Spring of 2011, on three occasions during which her responsiveness would be noted. There was no consensus between the experts as to whether a SMART assessment should be carried out but it was agreed that the applicant should not be prevented from arranging such an assessment provided it was undertaken following the outings in the following Spring.

29. At that stage, it appeared that the date provisionally fixed for the full hearing of the application for an order for the withdrawal of ANH, in the last two weeks in July 2011, might have to be abandoned. An application was therefore made to vacate the listing and adjourn it to later in the year. When the matter was put before me on paper, I was concerned that there should be no further delay in these proceedings which had already lasted nearly four years and therefore directed a telephone hearing take place at which I declined to order the vacation of the July listing and instead directed the parties to identify appropriate hearing dates which would be convenient for all experts and witnesses. It subsequently transpired that it would be possible for second SMART assessment to be completed and evaluated before July, and for the experts and other witnesses to attend, and the hearing has therefore gone ahead as scheduled. Meanwhile, at a further directions hearing in April, I directed that the parties were jointly to instruct Miss Gill-Thwaites to undertake the further SMART assessment of M at the care home between 3 May and 3 June 2011, to prepare a report on the results of the assessment by 9 June, and that, following the receipt of that report, the two medical experts should discuss and prepare a joint statement identifying all matters in which they agree or disagree.

30. Miss Gill-Thwaites duly carried out a further SMART assessment in May. She found that M was still in a minimally conscious state. The meaningful responses demonstrated during the formal part of the assessment were less consistent than in the earlier assessment, but the observations made by the team of carers were more frequent than those reported by her former carers in hospital in 2007. Mr. Badwan and Professor Turner-Stokes then prepared a joint report in which they agreed that M remained in a minimally conscious state, but disagreed about a number of other matters, including the ultimate question whether ANH should be withdrawn. They amplified on their views in further individual written reports prepared shortly before the final hearing. I shall consider and analyse the interpretation of the SMART assessment, and the further expert opinions, later in this judgment.

31. Meanwhile, when the matter had come before me at another directions hearing, I had, in accordance, with Rule 92(1) and Practice Direction 9E paragraph 16 of the Court of Protection Rules 2007, directed that, as the application involved issues concerning

serious medical treatment, the hearing should be conducted in open court. Not surprisingly, the prospect of a hearing in public caused some anxiety to the lay parties and at the hearing in April, I was accordingly invited to consider whether or not to exercise my powers under Rule 92(2) to make directions limiting or restricting the reporting of the proceedings. An order was made on that occasion in April, but following objections by the press, a further hearing was convened on 12 May at which I relaxed some of the restrictions and made an order, which remains in force, and has the effect of prohibiting, for the duration of M's lifetime or until further order, (a) the publication or broadcasting of any information likely to lead to the identification of M, the current and former parties to the proceedings, witnesses, current and past healthcare professionals and members of M's care team referred to in the proceedings, the care home where M resides, and any address or location referred to in the proceedings, save that the location may be stated to be the "north of England" and (b) any person bound by the order from (i) communicating with M, V, W or S; (ii) approaching within twenty metres of M; (iii) approaching within fifty metres of the care home for the purpose of seeking information about M and/or these proceedings; and (iv) taking any photograph of M, W, B or S. The reasons for my decision to make a reporting restriction order, and the full terms of the order, are set out in a judgment reported at [2011] EWHC 1197 (COP).

THE ISSUES

32. The two substantive issues to be determined in this case, as summarised by Miss Caroline Harry Thomas QC and Miss Katherine Apps on behalf of the Official Solicitor, are, first, whether it in M's best interests that all life sustaining treatment and medical support, including artificial nutrition and hydration (ANH) is withdrawn and withheld and, secondly, if it is in M's best interests to continue life sustaining treatment, including ANH, what future management is in her best interests. In the event, all parties agreed during the hearing that the court should deliver a judgment on the first issue and then reconvene a hearing to determine details of the care plan consequent upon the decision whether or not to sustain the treatment.

33. The following matters are accepted by all parties. First, the Court has jurisdiction to hear this application under the provisions of the Mental Capacity Act 2005 (MCA). Secondly, M lacks capacity to litigate and make decisions as to her medical treatment. Thirdly, there is no valid and applicable advance decision or lasting power of attorney under the MCA or any documented advance decision made by M before she suffered her brain injury. Fourthly, the Court has to determine the application by deciding whether the withholding/withdrawal of life sustaining treatment, including ANH, is in M's best interests, by reference to s.4 of MCA and the relevant line of authorities, principally ***Airedale NHS Trust v Bland*** [1993] AC 789.

34. The Applicant's case in summary is as follows. Medical science has developed from the 1990s when the concept of persistent or permanent vegetative state (originally "PVS" but now more commonly "VS") was first considered in the English courts. Since then medical science has recognised the concept of the minimally conscious state ("MCS"), which is a state just above that of vegetative state, but which also involves extremely significant limitations on consciousness with a quality of life that many would find impossible to accept were they able to consistently express themselves with full competence. The court has jurisdiction to decide what treatment patients in a minimally conscious state should receive. The issue in this case is

whether M continuing to have medical treatment in the form of ANH is truly in her best interests, as defined in s.4 of the Mental Capacity Act 2005 ("MCA").

35. There is however a difference between VS and MCS cases. In VS cases, the balance falls in one direction in every case – in favour of withdrawal. In MCS cases, it depends on the facts, and the expert evidence, in the particular case. In assessing where the patient's best interests lie, the court must follow a "balance-sheet" approach. The Applicant does not contend that all those in MCS result in the balance of best interests to be in favour of withdrawal – simply that in some individual cases, after meticulous consideration of all of the factors for and against – that might be the most humane course and in the individual's best interests. In this case it is important that the factors for and against withdrawing treatment are carefully examined and weighed in the balance, after mature reflection. The proper assessment of best interests in this context requires great weight to be given to M's wishes and feelings and those of her family, past and present. The interpretation of evidence as to M's behaviour is best performed by the neuro-rehabilitative experts, in particular Professor Turner-Stokes who concludes that M's experiences are predominantly negative. Accordingly, given M's clearly expressed views and paying particular attention to the type of person M was when fully sentient, it is in M's best interests for ANH to be withdrawn, and for her to be permitted to die with dignity.

36. In reply, the Official Solicitor's submissions on behalf of M can be summarised as follows. He accepts that, where a person is in the MCS and not clinically stable, whether the withdrawal or withholding of life sustaining treatment is in that person's best interests will depend on that person's best interests under s.4 of MCA. Withdrawal and/or withholding of life sustaining treatment may or may not be lawful depending on the circumstances. However, where, as in M's case, a person is in a MCS and is otherwise clinically stable, it can never be in that person's best interests to withdraw and/or withhold life sustaining treatment including ANH. To withdraw and/or withhold life sustaining treatment in such circumstances is unlawful and, if done intentionally, amounts to unlawful killing and murder; it would amount to a breach of M's rights under articles 2, 3 and 8 and (depending on the circumstances) 13 and 14 of the European Convention for the Protection of Human Rights and Fundamental Freedoms ("ECHR"). The Official Solicitor submits that, just as PVS cases do not involve a balance sheet analysis of best interests due to the specific and particular circumstances, cases involving people in a MCS who are clinically stable do not involve a balance sheet analysis of best interests, because of their particular and specific circumstances. He accepts that the Court under section 4 MCA must listen to and consider evidence from the family, clinicians and care staff. However, where a person is in a MCS and is otherwise clinically stable and well it can never be in their best interests, and therefore lawful to withhold or withdraw life sustaining treatment including ANH.

37. In the alternative, if a balance sheet approach is applicable, the Official Solicitor submits that the balance comes down clearly in favour of continuing ANH.

38. The Primary Care Trust ("PCT") joined as Second Respondent to the proceedings, does not support the Application for a declaration that it is in M's best interests for ANH to be withheld. In respect of the continued provision of life sustaining treatment for a person lacking capacity the PCT takes as its starting point the assumption that it is in the person's best interests for life to continue. The PCT accepts that in respect of

an incapacitated patient, where treatment is futile, overly burdensome or intolerable for the patient and where there is no prospect of recovery, it may be in the best interests of the patient to withdraw or withhold treatment, including in extreme circumstances, treatment that sustains life. However the balance between the benefits of continued treatment and the dis-benefits must be drawn.

39. On the factual and expert evidence it appears to the PCT that M's life is one that is not without positive elements. The PCT notes the reports of staff that M can express emotion and appears at times to experience pleasure, for example in response to certain music or care home personnel. It does not appear to the PCT that M's condition is such that her life has no positive aspects to weigh against the discomforts she may at times experience. The PCT notes the statements of M's partner and sister that they believe her previous expressed views indicate that she would not have wished to continue to live as she does. The PCT does not doubt the veracity of these accounts. However in the absence of any clear advance refusal of treatment or very clear and unambiguous exposition of the patient's wishes in anticipation of the particular situation that has arisen, the PCT cannot take the family's indication of M's preference as a direction as to how it should decide upon commissioning her treatment in this case. Whilst some weight should be given under s.4 MCA to an incapable patient's previous capable statements there is nothing in this case to indicate to the PCT that M made her previous statements with reference to the withdrawal of ANH from someone with consciousness. The PCT submits that the weight to be given to previous opinions expressed by M is in no way sufficient to tip the balance in favour of withdrawing of life sustaining measures in this case.

40. The summaries set out above are drawn from the preliminary skeleton arguments presented on behalf of the parties. At this point, I would like to acknowledge the outstanding work of all the legal representatives instructed in this case – Vikram Sachdeva and Victoria Butler-Cole, instructed by Yogi Amin of Irwin Mitchell assisted by Anne-Marie Irwin and Douglas Pyper, on behalf of the Applicant; Caroline Harry Thomas QC and Katherine Apps, instructed by Alistair Pitblado the Official Solicitor, assisted by James Beck and Beverley Taylor, on behalf of M; and Bridget Dolan, instructed by Paul McGough of Beachcroft LLP, on behalf of the PCT.

DISORDERS OF CONSCIOUSNESS AND THE PROCESS OF DIAGNOSIS

41. At the outset, it is important to define the terms used by clinicians to identify categories of disorders of consciousness, and to outline the assessment tools and scales used in diagnosis.

42. Current thinking recognises three categories of disorders of consciousness. In ascending order, the first is coma, which "represents a state of unarousable unresponsiveness in which there is no evidence of self-awareness or environmental awareness. The eyes remain continuously closed, purposeful responses to environmental stimuli cannot be elicited, and there is no evidence of discrete localising responses or language comprehension and expression" (Seel et al, "Assessment Scales for Disorders of Consciousness: Evidence-based Recommendations for Clinical Practice and Research", Arch Phys Med Rehabil Vol 91, December 2010).

43. The second category is vegetative state ("VS"). The term "persistent vegetative state" was first coined nearly forty years ago by Jennett and Plum, although recent research papers indicate that "vegetative state" is now preferred to "persistent" or "permanent vegetative state" as the most appropriate term to describe this condition. The diagnostic criteria for VS have been summarised as follows:

> "this disorder is characterised by the complete absence of behavioural evidence for awareness of self and environment, with preserved capacity for spontaneous or stimulus-induced arousal …. [A]ll of the following criteria must be met to establish the diagnosis of VS: (1) No evidence of awareness of self or environment. (2) No evidence of sustained, reproducible, purposeful or voluntary behavioural responses to visual, auditory, tactile or noxious stimuli. (3) No evidence of language comprehension or expression. (4) Intermittent wakefulness manifested by the presence of sleep-wake cycles (i.e. periods of eye-opening). (5) Sufficient preservation of autonomic functions to permit survival with adequate medical care. (6) Bowel and bladder incontinence. (7) Variable preservation of cranial nerve and spinal reflexes." (Giacino and Kalmar (2005) "Diagnostic and prognostic guidelines for the vegetative and minimally conscious states", Neuropsychological Rehabilitation 15(3/4) 166-174)

44. The third category, known as the minimally conscious state ("MCS"), was identified and defined by the Aspen Neurobehavioural Conference Workgroup as explained in a seminal article in 2002, (Giacino et al, "The minimally conscious state: definition and diagnostic criteria", Neurology, 68: 304-307). They defined MCS as

> "a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated". The Aspen Group defined the diagnostic criteria for MCS, so as to distinguish it from VS, by "the presence of behaviours associated with conscious awareness. In MCS, cognitively mediated behaviour occurs inconsistently, but is reproducible or sustained long enough to be differentiated from reflexive behaviour. The reproducibility of such evidence is affected by both the consistency and complexity of the behavioural response. Extended assessment may be required to determine whether a simple response (e.g. finger movement or eye blink), that is observed infrequently is occurring in response to a specific environmental event (e.g. command to move fingers or blink eyes) or on a coincidental basis. In contrast, a few observations of a complex response (intelligible verbalisation) may be sufficient to determine the presence of consciousness."

45. The Aspen group continued: "To make the diagnosis of MCS, limited but clearly discernible evidence of self or environmental awareness must be demonstrated on a reproducible or sustained basis by one or more of the following behaviours:

- Following simple commands
- Gestural or verbal yes/no responses (regardless of accuracy)
- Intelligible verbalisation

> - Purposeful behaviour, including movements of affective behaviours that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity. Some examples of qualifying purposeful behaviour include
>   - appropriate smiling or crying in response to the linguistic or visual content of emotional but not to neutral topic or stimuli
>   - vocalisations or gestures that occur in direct response to the linguistic content of questions
>   - reaching for objects that demonstrates a clear relationship between object location and direction of reach
>   - touching or holding objects in a manner that accommodates the size and shape of the object
>   - pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli.”

46. Both Professor Turner-Stokes and Mr. Badwan confirmed in oral evidence that at the moment there is no clear definition of various levels of consciousness within the MCS. It is clear, however, that there is a spectrum of minimal consciousness extending from patients who are only just above the vegetative state to those who are bordering on full consciousness.

47. As Professor Turner-Stokes said in evidence, some patients go from VS into a MCS, others go from coma to MCS, and of those in MCS some emerge into full consciousness. In cross-examination, she acknowledged that two research studies had demonstrated that some patients do emerge from MCS after periods measured in years: see Lammi et al (2005) “The minimally conscious state and recovery potential: a follow-up study 2 to 5 years after traumatic brain injury”, Archives of Physical Medicine and Rehabilitation 86: 746-754 – in which the authors concluded inter alia that “the low correlation coefficients between duration of MCS and the outcome measures suggest that prognostic statements based on length of time a person is in the MCS cannot be made with confidence” – and Luauté et al (2010) “Long-term outcomes of chronic minimally conscious and vegetative states”, Neurology 75: 246-252. However, the prospects of anyone emerging from MCS after eight years are, in Professor Turner-Stokes’s view, remote, and there is nothing in either research paper to contradict that view. Indeed, the Luauté paper, whilst confirming that the potential for unfavourable outcomes was significantly greater in PVS than in MCS, also confirmed the “generally very poor functional prognosis of non-traumatic brain injury”.

48. Clinical diagnosis of the level of consciousness is exceedingly difficult. As Professor Turner-Stokes said in her oral evidence, behavioural observation is the best tool we have for assessing low awareness states. In the recent article by Seel et al (2010) “Assessment Scales for Disorders of Consciousness: Evidence-based Recommendations for Clinical Practice and Research”, (*supra*), the authors summarised the difficulties facing clinicians seeking to diagnose the level of consciousness in a patient:

> “Consciousness cannot be directly observed. Therefore, clinical assessment of persons with disorders of consciousness relies on observing behaviour and drawing inferences about the underlying state of consciousness.

> Detection of behavioural signs of consciousness is subject to interrater variability and is often confounded by unpredictable fluctuations in arousal, underlying sensorimotor impairment, unrecognised cognitive and language deficits, and sedating medications. Even where there is agreement about the behaviour observed, there may be assessor variability when inferring consciousness."

49. A number of processes have been developed across the world for making such assessments, of variable quality. Commonly these tools are patented so their use may be restricted. In this country, the two principal assessment tools in use for diagnosing consciousness are the Sensory Modality Assessment and Rehabilitation Technique ("SMART") and the Wessex Head Injury Matrix ("WHIM").

50. The SMART provides a very detailed graded assessment of the patient's level of sensory motor and communicative responses to a structured and regulated sensory stimulation programme. SMART assessors require formal training and accreditation. The SMART is comprised of two components – the formal component, conducted by the SMART assessor including the SMART sensory assessment and the SMART behavioural observational assessment, and an informal component consisting of information from family and carers regarding observed behaviours and pre-morbid interests likes and dislikes. The SMART behavioural observation assessment is carried out during a ten-minute quiet period prior to commencing the SMART sensory assessment in which the assessor observes and becomes familiar with the patient's reflexive, spontaneous and purposeful behaviour. The SMART formal assessment is conducted in ten sessions within a three week period with an equal number of sessions in the morning and the afternoon. Within the SMART sensory assessment, there are eight SMART modalities, including five sensory modalities (visual, auditory, tactile, olfactory and gustatory) and three other modalities (motor function, function communication and wakefulness). The assessment consists of twenty-nine standardised SMART techniques, offering a range of stimuli such as assessment of response to visual threat, response to light, touch and taste, visual tracking and following specific written instructions. The SMART five point hierarchical scale is consistent across all of the seven modalities. The five levels are (1) no response (2) reflexive and generalised responses (3) withdrawal (e.g. turning head away) (4) localising (e.g. turning head or moving upper limbs towards stimuli) and (5) discriminating responses following visual or auditory commands or using objects appropriately. A consistent response on five consecutive assessments at SMART level 5 in any of the five sensory modalities e.g. following verbal instructions, indicates a meaningful response. These behaviours are inconsistent with VS and are indicative of MSC or higher levels of functioning.

51. The WHIM is a sixty two-itemed hierarchical scale, which provides a sequential framework of tightly defined categories of observation covering an individual's level of responsiveness and interaction with their environment. It was developed to identify changes from coma through to emergence from post-traumatic amnesia in patients with traumatic brain injury, but it also has applicability in other causes of disorders of consciousness. Behaviours may occur either spontaneously or in response to stimulation. The tool does not require specific accreditation and it is designed to be used by different members of the multi-disciplinary team. Because it can be easily applied in the course of clinical practice, it provides a useful serial

record which can be used to monitor the consistency of response as well as trends towards change over time.

52. The clinical team that developed the WHIM recognised at an early stage that it had some limitations:

> "The WHIM is an objective tool. Operational definitions for each behaviour state clearly the criteria by which a behaviour is judged to occur. The disadvantage of the definitions is that they may be perceived as rigid and preclude recording of significant behaviours which do not reach these criteria" (Shiel et al "The WHIM main scale: a preliminary report of the scale to assess and monitor patient recovery after severe brain injury" (2000) Clinical Rehabilitation, 14: 408-416).

In oral evidence, Professor Turner-Stokes pointed out that the WHIM, which is now over ten years old, is "in need of an overhaul. Some of the assumptions underpinning it as to the significance of certain behaviours (for example, smiling) need rethinking". Experience has shown that some of the types of behaviour are in the wrong position in the hierarchy, which require adjustments to be made when analysing the results of the assessment. Mr. Badwan was more sceptical of the utility of the WHIM in assessing patients in MCS. I accept the view of Professor Turner-Stokes, however, that the WHIM will remain an important assessment tool, particularly when used in conjunction with the SMART and over time, especially at the higher levels of consciousness.

53. Professor Turner-Stokes distinguished the use of SMART and WHIM as follows. The SMART is a very detailed systematic assessment under controlled stimulation delivered over three weeks by trained and accredited personnel. The WHIM is what Professor Turner-Stokes described as a broader tool designed to be used by any clinician in the course of interacting with the patient when they simply record types of behaviour they observe. It is relatively quick and easy to carry out and can be repeated by other clinicians. Professor Turner-Stokes described how this is particularly useful in MCS cases in which a feature of the condition is inconsistency of behaviour. The WHIM is very helpful in determining the amount of time the patient does and does not demonstrate a particular type of behaviour. Whereas the SMART is primarily designed to diagnose whether or not a patient is in a VS or a MCS, the WHIM, in Professor Turner-Stokes' experience, (although not yet confirmed by published research), allows clinicians to track a patient's progress through a MCS. Thus both tools play a very important part in the diagnosis and treatment of low awareness states.

54. SMART and WHIM are widely recognised and respected, in this country and internationally. In the article by Seel and others cited above, it was reported that the Disorders of Consciousness Task Force, having carried out a systematic review of a number of behavioural assessment scales for disorders of consciousness, concluded that both the SMART and the WHIM demonstrated good content validity and contained items that could distinguish persons who are in a VS, in a MCS, or have emerged from MCS. It should be noted, however, that the authors of that research stated that there has been no validation study for detecting meaningful change along a continuum of disorders of consciousness, which confirms Professor Turner-Stokes'

evidence that the use of serial WHIM tests to track progress over time is “not yet in the literature”.

55. Over the past twenty years, medical understanding about PVS and MCS has progressed very considerably. In particular, the development of the assessment tools such as SMART has increased knowledge about these conditions. Earlier guidance is now somewhat out of date, for example the working party report on “The Vegetative State” published by the Royal College of Physicians in 2003 which was produced before the SMART was available. Both experts in this case regarded the RCP guidance as now out of date – Mr. Badwan described it as having “a lot of problems”. Professor Turner-Stokes is chairing a committee established to update this guidance.

56. With greater understanding of disorders of consciousness has come a recognition, cited by Helen Gill-Thwaites and acknowledged by Professor Turner-Stokes, that a very significant proportion of patients who were diagnosed as being in a VS prior to the development of assessment tools such SMART have subsequently been re-diagnosed as in a MCS. Seel et al (supra) on behalf of the American Congress of Rehabilitation Medicine Disorders of Consciousness Task Force, note that “diagnostic errors in classifying persons in an MCS as being in a VS have been reported to range from 30% to 40% and can have adverse consequences for clinical treatment”.

THE LAW

Origins of the declaratory jurisdiction

57. Counsel on behalf of the three parties presented lengthy legal submissions citing a large number of authorities not only from this jurisdiction but also from the European Court of Human Rights, the United States, the Commonwealth and the Republic of Ireland. As this is said to be the first occasion in this country in which an application for the withdrawal of ANH has been made in respect of a person in a minimally conscious state, it was entirely appropriate for counsel to take this course, and I am very grateful to them for their diligent efforts. It is, however, important that this court should resist the temptation to stray beyond the issues that arise in this specific case. In particular, I bear in mind the warning delivered by Lord Phillips of Worth Matravers MR in *R (Burke) v GMC (Official Solicitor and others intervening)* [2005] EWCA Civ 1003, [2006] QB 273 at para 21 that

> “there are great dangers in a court grappling with issues … when these are divorced from a factual context that requires their determination. The court should not be used as a general advice centre. The danger is that the court will enunciate propositions of principle without full appreciation of the implications that these will have in practice, throwing into confusion those who feel obliged to attempt to apply those principles in practice. This danger is particularly acute where the issues raised involve ethical questions that any court should be reluctant to address, unless driven to do so by the need to resolve a practical problem that requires the court’s intervention.”

58. Historically, the jurisdiction in respect of persons of unsound mind was exercised under the prerogative of the Crown as *parens patriae* to protect the persons and property of those unable to do so for themselves. The jurisdiction in respect of children evolved into the modern wardship jurisdiction, but that in respect of persons

of unsound mind was abolished by statute in 1959. In wardship, a remedy was evolved by which the Family Division gave directions as to the medical treatment of a child, and in a series of cases directed that a child should be treated in accordance with expert recommendations that it would not be in his best interests to continue life-sustaining treatment: see *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33. The absence of a *parens patriae* jurisdiction prevented such orders in cases of adults, but in 1989 the House of Lords endorsed the use of the inherent jurisdiction to make declarations as to the lawfulness of medical treatment for persons who lack mental capacity: *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1. The nature of the jurisdiction was summarised in that case by Lord Brandon of Oakbrook at page 64.

> "The substantive law is that a proposed operation is lawful if it is in the best interests of the patient, and unlawful if it is not. What is required from the court, therefore, is not an order giving approval to the operation, so as to make lawful that which would otherwise be unlawful. What is required from the court is rather an order which establishes by judicial process … whether the proposed operation is in the best interests of the patient and therefore lawful, or not in the patient's best interests and therefore unlawful."

The House further stated that the standard which the court should apply in deciding whether a proposed operation was or was not medically in the best interests of the patient was the test laid down in *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582, namely, that it is in accordance with a practice accepted at the time by a responsible body of medical opinion skilled in the particular form of treatment in question (per Lord Brandon at page 68). The House of Lords stressed, however, that the ultimate decision as to whether the proposed treatment is in the patient's best interests is a matter for the court. "In all proceedings where expert opinions are expressed, those opinions are listened to with great respect; but, in the end, the validity of the opinion has to be weighed and judged by the court" (per Lord Goff of Chieveley at page 80).

59. Thus at the birth of the declaratory jurisdiction concerning incapacitated adults one finds a clear acknowledgement that its exercise involves a judicial process whereunder the expert medical and other evidence is weighed to determine where the best interests of P lie.

60. It was subsequently observed on a number of occasions that this declaratory jurisdiction created by the courts in relation to adults who lacked capacity was for all practical purposes the same as the *parens patriae* jurisdiction: see e.g. dicta of Thorpe LJ in *Re S (Adult Patient: Sterilisation)* [2001] Fam [2000] 2 FLR 289 at 29–30 and 403 respectively, and of Munby J (as he then was) in *A v A Health Authority and others; Re J and Linked Applications)* [2002] EWHC 18 (Fam/Admin) [2002] 1 FLR 845 at para 45, and in *Re SA (Vulnerable Adult with Capacity: Marriage)* [2005] EWHC 2941 (Fam) [2006] 1 FLR 86 at para 37.

The decision in *Bland*

61. Anthony Bland sustained catastrophic and irreversible brain damage as a result of being crushed during the Hillsborough stadium disaster in April 1989. The unanimous medical diagnosis was that he was in a PVS without any hope of recovery or

improvement. With the full support of his family and the medical team responsible for his treatment, the health authority responsible for the hospital where he was being treated applied to the High Court for declarations that they might lawfully discontinue all life-sustaining treatment and medical support designed to keep him alive, including the termination of artificial ventilation, nutrition and hydration, and further that they might lawfully cease providing medical treatment save for the purpose of enabling him to end his life and die peacefully with the greatest dignity and the least pain, suffering and distress. The President of the Family Division (Sir Stephen Brown) granted the declarations, and his order was upheld by the Court of Appeal (Sir Thomas Bingham MR, Butler-Sloss and Hoffman LJJ) and the House of Lords (Lords Keith of Kinkel, Goff of Chieveley, Lowry, Browne-Wilkinson and Mustill).

62. All five Law Lords delivered speeches and a great deal of academic ink has been spilt in analysing the different nuances and emphases in those speeches. Although some submissions were made to me about these nuances, and about some of the dicta in the judgments of the Court of Appeal, I do not consider it necessary to refer to those matters in this judgment. It is generally accepted that the principal speech in the House of Lords was delivered by Lord Goff from which I cite the following passages relevant to the present case:

> “[T]he fundamental principle is the principle of the sanctity of human life - a principle long recognised not only in our own society but also in most, if not all, civilised societies throughout the modern world, as is indeed evidenced by its recognition both in article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (1953) (Cmd. 8969), and in article 6 of the International Covenant of Civil and Political Rights 1966. But this principle, fundamental though it is, is not absolute. Indeed there are circumstances in which it is lawful to take another man's life, for example by a lawful act of self-defence …. [T]here is no absolute rule that the patient's life must be prolonged by such treatment or care, if available, regardless of the circumstances. 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 more important, the doctor's duty to act in the best interests of his patient must likewise be qualified …. Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it; though in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred: see, e.g., *In re T. (Adult: Refusal of Treatment)* [1993] Fam 95 …. But in many cases not only may the patient be in no condition to be able to say whether or not he consents to the relevant treatment or care, but also he

> may have given no prior indication of his wishes with regard to it. In the case of a child who is a ward of court, the court itself will decide whether medical treatment should be provided in the child's best interests, taking into account medical opinion. But the court cannot give its consent on behalf of an adult patient who is incapable of himself deciding whether or not to consent to treatment. I am of the opinion that there is nevertheless no absolute obligation upon the doctor who has the patient in his care to prolong his life, regardless of the circumstances. Indeed, it would be most startling, and could lead to the most adverse and cruel effects upon the patient, if any such absolute rule was held to exist. It is scarcely consistent with the primacy given to the principle of self-determination in those cases in which the patient of sound mind has declined to give his consent, that the law should provide no means of enabling treatment to be withheld in appropriate circumstances where the patient is in no condition to indicate, if that was his wish, that he did not consent to it." (pp 863-5)

63. Later, he continued:

> "I return to the patient who, because for example he is of unsound mind or has been rendered unconscious by accident or by illness, is incapable of stating whether or not he consents to treatment or care. In such circumstances, it is now established that a doctor may lawfully treat such a patient if he acts in his best interests, and indeed that, if the patient is already in his care, he is under a duty so to treat him: see *In re F. (Mental Patient: Sterilisation)* [1990] AC 1, in which the legal principles governing treatment in such circumstances were stated by this House. For my part I can see no reason why, as a matter of principle, a decision by a doctor whether or not to initiate, or to continue to provide, treatment or care which could or might have the effect of prolonging such a patient's life, should not be governed by the same fundamental principle. Of course, in the great majority of cases, the best interests of the patient are likely to require that treatment of this kind, if available, should be given to a patient. But this may not always be so …. The doctor who is caring for such a patient cannot, in my opinion, be under an absolute obligation to prolong his life by any means available to him, regardless of the quality of the patient's life. Common humanity requires otherwise, as do medical ethics and good medical practice accepted in this country and overseas. As I see it, the doctor's decision whether or not to take any such step must (subject to his patient's ability to give or withhold his consent) be made in the best interests of the patient …. It is of course the development of modern medical technology, and in particular the development of life support systems, which has rendered cases such as the present so much more relevant than in the past. Even so, where (for example) a patient is brought into hospital in such a condition that, without the benefit of a life support system, he will not continue to live, the decision has to be made whether or not to give him that benefit, if available. That decision can only be made in the best interests of the patient. No doubt, his best interests will ordinarily require that he should be placed on a life support system as soon as necessary, if only to make an accurate assessment of his condition and a prognosis for the future. But if he neither recovers sufficiently to be taken

> off it nor dies, the question will ultimately arise whether he should be kept on it indefinitely. As I see it, that question (assuming the continued availability of the system) can only be answered by reference to the best interests of the patient himself, having regard to established medical practice. Indeed, if the justification for treating a patient who lacks the capacity to consent lies in the fact that the treatment is provided in his best interests, it must follow that the treatment may, and indeed ultimately should, be discontinued where it is no longer in his best interests to provide it." (pp 866-867).

64. Lord Goff continued:

> "a distinction may be drawn between (1) cases in which, having regard to all the circumstances (including, for example, the intrusive nature of the treatment, the hazards involved in it, and the very poor quality of the life which may be prolonged for the patient if the treatment is successful), it may be judged not to be in the best interests of the patient to initiate or continue life-prolonging treatment, and (2) cases such as the present in which, so far as the living patient is concerned, the treatment is of no benefit to him because he is totally unconscious and there is no prospect of any improvement in his condition. In both classes of case, the decision whether or not to withhold treatment must be made in the best interests of the patient. In the first class, however, the decision has to be made by weighing the relevant considerations. For example, in *In re J. (A Minor) (Wardship: Medical Treatment* [1991] Fam 33, the approach to be adopted in that case was stated by Taylor L.J. as follows, at p. 55: 'I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child.' With this class of case, however, your Lordships are not directly concerned in the present case; and though I do not wish to be understood to be casting any doubt upon any of the reported cases on the subject, nevertheless I must record that argument was not directed specifically towards these cases, and for that reason I do not intend to express any opinion about the precise principles applicable in relation to them. By contrast, in the latter class of case, of which the present case provides an example, there is in reality no weighing operation to be performed. 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 regarded as being, in medical terms, useless ….[F]or 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 in 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, which must cause considerable distress to his family - a distress which reflects not only their own feelings but their perception of the situation of their relative who

> is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination" (pp 868-9).

65. The key principles to be drawn from these core passages in Lord Goff's speech are as follows: (1) the principle of the sanctity of life is fundamental; (2) that principle is not, however, absolute and may yield in certain circumstances, for example to the principle of self-determination; (3) a decision whether ANH treatment should be initiated or withdrawn must be determined by what is in the best interests of the patient; (4) in the great majority of cases the best interests of the patient were likely to require that the treatment should be given; (5) there was a category of case in which the decision whether to withhold treatment would be made by weighing up relevant and competing considerations, but (6) such an approach was inappropriate in the case of Anthony Bland as the treatment had no therapeutic purpose and was "futile" because he was unconscious and had no prospects of recovery.

66. In addition to these core principles, the speeches in the *Bland* case provide further guidance for the current case in a number of other respects.

67. First, Lord Keith reiterated the principle, derived from the earlier House of Lords decision in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, that it is unlawful, so as to constitute both a tort and the crime of battery, to administer medical treatment to an adult, who is conscious and of sound mind, without his consent.

> "A person is completely at liberty to decline to undergo treatment, even if the result of his doing so will be that he will die. This extends to the situation where the person, in anticipation of his, through one cause or another, entering into a condition such as PVS, gives clear instructions that in such event he is not to be given medical care, including artificial feeding, designed to keep him alive" (p 857)'

68. Secondly, as recorded by Lord Goff (at p 862), it was accepted by all parties, again following the earlier decision in *Re F*, that proceedings for declaratory relief were the most appropriate means for providing authoritative guidance as to the lawfulness of withholding ANH. Further, the House of Lords accepted the view of Sir Stephen Brown P. at first instance, endorsed by the Master of the Rolls in the Court of Appeal, that doctors should, as a matter of practice, seek the guidance of the court by way of an application for declaratory relief, before withholding life-prolonging treatment from a PVS patient (see Lord Keith at p 859 E to G and Lord Goff at pp 873 to 874).

69. Thirdly, Lord Goff recorded (at p 870)

> "there is overwhelming evidence that, in the medical profession, artificial feeding is regarded as a form of medical treatment; and even if it is not strictly medical treatment, it must form part of the medical care of the patient. Indeed, the function of artificial feeding in the case of Anthony, by means of a nasogastric tube, is to provide a form of life support analogous to that provided by a ventilator which artificially breathes air in and out of the lungs of a patient incapable of breathing normally, thereby enabling oxygen to reach the bloodstream. The same principles must apply in either case when the question is asked whether the doctor in charge may lawfully discontinue the life-sustaining treatment or care; and if in either case the

> treatment is futile in the sense I have described, it can properly be concluded that it is no longer in the best interests of the patient to continue it."

70. Fourthly, Lord Goff acknowledged that the discontinuance of ANH would result in the patient starving to death, which normally leads to pain, suffering and distress. In that case, however, it was "clear from the evidence that no such pain or distress will be suffered by Anthony, who can feel nothing at all."

71. Finally, Lord Goff stated (at p 871) that the so-called "substituted judgment" test adopted in most American courts – whereby "the court seeks, in a case in which the patient is incapacitated from expressing any view on the question whether life-prolonging treatment should be withheld in the relevant circumstances, to determine what decision the patient himself would have made had he been able to do so" – did not form part of English law in relation to incompetent adults, "on whose behalf nobody has power to give consent to medical treatment".

Case law following *Bland*

72. Following *Re F* and *Bland*, the principles and practical aspects of the declaratory jurisdiction were refined in a number of cases over the following twelve years, from which I cite the following points of relevance to the present case.

73. First, the burden of establishing that discontinuance of treatment is in a person's best interests is always on those who assert that life-sustaining treatment be withdrawn. In R (Burke) v GMC (supra) Munby J (as he then was) expressed this point in this way (in a passage approved by the Court of Appeal in that case):

> "There is a very strong presumption in favour of taking all steps which will prolong life, and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In case of doubt, that doubt falls to be resolved in favour of the preservation of life."

74. Secondly, in determining the best interests of an incapacitated adult, the courts developed the use of a "balance sheet" approach, as explained by Thorpe LJ in *Re A (Male Sterilisation)* [2000] 1 FLR 549 560 F-H:

> "Pending the enactment of a checklist or other statutory direction it seems to me that the first instance judge with the responsibility to make an evaluation of the best interests of a claimant lacking capacity should draw up a balance sheet. The first entry should be of any factor or factors of actual benefit. In the present case the instance would be the acquisition of foolproof contraception. Then on the other sheet the judge should write any counterbalancing dis-benefits to the applicant. An obvious instance in this case would be the apprehension, the risk and the discomfort inherent in the operation. Then the judge should enter on each sheet the potential gains and losses in each instance making some estimate of the extent of the possibility that the gain or loss might accrue. At the end of that exercise the judge should be better placed to strike a balance between the sum of the certain and possible gains against the sum of the certain and possible losses.

> Obviously, only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant."

75. Thirdly, in drawing up the balance sheet, the Court is not concerned solely with medical issues, but also takes into account wider factors concerning the individual. Butler-Sloss P observed in *Re A (Male Sterilisation)* that "best interests encompasses medical, emotional and all other welfare issues", and in *A Hospital NHS Trust v S, DG and SG* [2003] EWHC 365 (Fam) at para 47 that the court had to consider the effect of any proposed treatment on the patient's enjoyment of life. In *Re S (Adult Patient: Sterilisation)* [2001] Fam 15 at page 30 Thorpe LJ stated:

> "in deciding what is best …. the judge must have regard to …. welfare as the paramount consideration. That embraces issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination."

To this, Hedley J at first instance in *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam) [2005] 1 FLR 21 added:

> "the infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests."

76. Fourthly, it was suggested at one stage that, before ANH could be withdrawn from a patient who was in a condition other than a VS, the circumstances had to be intolerable to the patient. The origin of this approach lay in dicta in two earlier cases in the Court of Appeal – in the judgments of Templeman and Dunn LJJ in *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421 and the judgment of Taylor LJ in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at page 55 – and it found its clearest exposition in the following passage in the judgment of Munby J at first instance in *R (Burke) v GMC (Official Solicitor intervening)* [2004] EWHC 1879 (Admin), [2005] QB 424 at para 111 (a case involving a claim for judicial review of guidance issued by the GMC about the administration of ANH):

> "…when considering whether to withhold or withdraw ANH from an incompetent patient, (1) the assessment of best interests has to be made from the point of view or perspective of the particular patient and (2) the touchstone of best interests in this context is intolerability."

Shortly after Munby J's decision in *Burke* at first instance, the "intolerability" test received apparent endorsement by Brooke LJ in the Court of Appeal in *W Healthcare NHS Trust v H* [2004] EWCA Civ 1324, [2005] 1 WLR 834. When, however, the *Burke* case itself arrived in the Court of Appeal a few months later, (reported at [2005] EWCA Civ 1003, [2006] QB 273) Lord Phillips of Worth Matravers MR, giving the judgment of the court, commented (at paragraph 63): "we do not think it possible to attempt to define what is in the best interests of a patient by a single test". This view was subsequently reiterated in another case in that Court, namely *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181, [2005] 1 WLR 3995. Giving the judgment of the Court, Wall LJ (as he then was) noted at para 76 that the dicta cited from *Re B* in support of the intolerability test had been ex tempore and not approved by the majority in *Re J*, that the observations of Brooke LJ in *W Healthcare NHS Trust v H* had been obiter and immaterial to the disposal of the appeal in that case, and that Hedley J at first instance in the *Wyatt* case had been right to see the "intolerability" concept as neither a gloss nor a supplementary test to best interests but, at most, a valuable guide in the search for best interests. Wall LJ concluded:

> "the forensic debate should, in our judgment, be unfettered by any potentially contentious glosses on the best interests test which are likely either inappropriately to shift the focus of the debate, or to restrict the broad exercise of the judicial discretion involved in balancing the multifarious factors in the case."

77. Fifthly, although there is (so far as counsel have been able to detect) no reported case in which a court has been asked to authorise the withdrawal of ANH from a patient diagnosed as being in a MCS, there have been cases in which courts have authorised the withholding or withdrawal of life-sustaining treatment from patients not in a PVS. In *Re D (Adult: Medical Treatment)* [1998] 1 FCR 498, Sir Stephen Brown held that it was not in the best interests of a patient to be kept alive by ANH who met most but not all of the clinical criteria for the diagnosis of PVS according to the 1996 guidelines produced by the Royal College of Physicians. All the medical expert witnesses were agreed, however, that the patient "had no degree of awareness whatsoever" and the President concluded that "all the evidence establishes, to my satisfaction, that there is no evidence of any meaningful life whatsoever". He stated that he did not believe "that, if a declaration were to be granted in this case, it would be extending the range of cases in which a declaration might properly be considered" (page 508). In *An NHS Trust v A and SA* [2005] EWCA Civ 1145, [2005] All ER (D) 07, the Court of Appeal upheld a declaration by Kirkwood J that it was lawful to discontinue ventilation and renal support of an elderly terminally-ill patient who lacked capacity to consent but retained consciousness and was able to respond to questions. In *Portsmouth Hospitals NHS Trust v Wyatt* (supra), a case concerning a two-year-old child born fourteen weeks prematurely and suffering from chronic respiratory and kidney problems with profound brain damage, Hedley J at first instance, upheld by the Court of Appeal, made a series of declarations unlimited in time authorising doctors to withhold ventilation in the event that the child suffered an infection that led or might lead to a collapsed lung. In *An NHS Trust v MB (A Child)* [2006] EWHC 507 (Fam), [2006] 2 FLR 319, a case concerning an 18-month-old child suffering from a very severe and degenerating form of spinal muscular atrophy, who was being artificially ventilated and fed, was suffering pain and discomfort from associated medical procedures, and had a short life expectancy but was not in a PVS and was aware of his surroundings, Holman J, having carried out a comprehensive balancing exercise, refused an application on behalf of the doctors for a declaration authorising the withdrawal of ventilation but granted a declaration authorising the withholding of further procedures, such as CPR and the administration of intravenous antibiotics, which would mean that the child had moved naturally towards his death despite the ventilation and involve the infliction of further pain. In *Re K (Medical Treatment: Declaration)* Sir Mark Potter P. made a declaration that it was lawful for doctors to discontinue giving parenteral nutrition to a six-month-old child who had been born prematurely with a severe neuromuscular disorder causing chronic muscle weakness and associated learning disability. Total parenteral nutrition had been

provided since she was one month old, and was affecting liver function which was likely to lead to liver failure at around one year of age. The child had some appreciation of what went on around her, but suffered regular discomfort and distress.

The Mental Capacity Act 2005

78. In 2005, Parliament enacted the Mental Capacity Act to provide a comprehensive statutory regime for making decisions about mentally incapacitated adults. The Act is supported by a Code of Practice. Jurisdiction in respect of such persons was transferred to a new Court of Protection. New rules of court – the Court of Protection Rules 2007 ("COPR") – were introduced governing the procedure of the Court, supported by a raft of practice directions. Although many of the procedures were new, the Act drew substantially on the principles and practices that had evolved under the inherent jurisdiction. Thus, the Act provided the new Court of Protection a statutory power to make declarations as to whether a person ("P") has or lacks capacity to make a decision and as to the lawfulness or otherwise of any act done, or yet to be done, in relation to that person: s.15. In addition, the Court has the power to make decisions on behalf of P in relation to P's personal welfare and property and affairs: s.16. The powers to make decisions as to personal welfare include, inter alia, the power to give or refuse consent to the carrying out or continuation of a treatment by a person providing health care for P: s.17(1)(d). Under the previous law following *Bland*, decisions about the proposed withholding or withdrawing of ANH from a person in a PVS were obliged to seek a declaration from the High Court. PD9E paragraph 5 repeats this requirement, but notably extends the obligation to bring cases before the Court of Protection to those involving decisions about the proposed withdrawing of such treatment from a person in a minimally conscious state. Where an application is to be made to the court in relation to the lawfulness of withholding or withdrawing artificial nutrition and hydration, from a person in a permanent vegetative state or a minimally conscious state, the proceedings must be conducted by the President of the Court of Protection or another judge nominated by him, in practice another High Court judge: COPR rule 86, PD 9E para 11 and PD 12A para 2. Thus the lawfulness or otherwise of withholding ANH will continue to be determined by declaratory proceedings usually conducted by judges of the Family Division sitting in the Court of Protection.

79. The basic principles to be applied under the Act are set out in s.1 and include, under s.1(4) the cardinal principle that "an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests". The steps to be taken to determine what is in a person's best interests are set out in s.4 which provides inter alia:

> "(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."

80. Further guidance is given in the Code of Practice – section 5 headed: "What does the Act mean when it talks about 'best interests'?" The Code of Practice at paragraphs 5.29 to 5.36 gives specific guidance as to how to work out someone's best interests when making decisions about life-sustaining treatment. In particular, at para 5.31 the Code states:

> "All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment."

81. It is important to note that, while any decision maker, including a judge, is under an obligation to consider P's wishes and feelings, and the beliefs, values and other factors that he would have taken into account if he had capacity, the decision must be based on P's best interests and not on what P would have decided if he had capacity. Like Lewison J (as he then was) in *Re P (Statutory Wills)* [2009] EWHC 163 (Ch) [2010] Ch 33, I agree with the observation in the explanatory notes to the original

Mental Capacity Bill (which in turn echoed the observation of Lord Goff in the *Bland* case cited above) that "best interests is not a test of 'substituted judgement' (what the person would have wanted), but rather it requires a determination to be made by applying an objective test as to what would be in the person's best interests." This is confirmed by the Code of Practice at paragraph 5.38:

> "In setting out the requirements for working out a person's 'best interests', section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests. Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests."

82. In passing, it should be emphasised that decisions about the proposed withholding or withdrawal of ANH from a person in a VS or MCS should always be brought to the court, as specifically required by para 5 of the COP Practice Direction 9E. In closing submissions, Miss Harry Thomas on behalf of the Official Solicitor drew attention to para 5.33 of the Code of Practice, which states inter alia that

> "Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests."

The Official Solicitor submits that the Code in this instance does not accurately reflect the law. The accuracy or otherwise of the Code is not a matter on which I have heard detailed submissions, and its impact on other types of treatment does not fall to be considered in this application. So far as ANH is concerned, the legal position has been clear since the decision in *Bland* and is as set out in the Practice Direction: all decisions about the proposed withholding or withdrawal of ANH from a person in a PVS or MCS should always be brought to the court.

Advance decisions

83. As set out above, Lord Goff of Chieveley in *Bland* had endorsed the right of a patient to make an advance decision to refuse treatment, and prior to the passing of the 2005 Act, the High Court had on occasions declared lawful a decision to discontinue giving ANH to an incapacitated adult in accordance with his wishes freely expressed at a time when the patient had capacity and understood the nature and consequences of the decision: see e.g. *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129. In that case, Hughes J, amplifying on the comments made by Lord Goff as to the safeguards needed in such circumstances:

> "Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes

> was made. All the circumstances in which the expression of wishes was given will of course have to be investigated."

In the case of *Re AK*, which concerned a young man suffering from motor neurone disease, the judge was satisfied that his expressions of wishes were "recent and … made not on any hypothetical basis but in the fullest possible knowledge of impending reality".

84. These judge-made provisions have now been superseded by s 24 to 26 of the Act which makes statutory provision for advance decisions to refuse treatment. An "advance decision" is defined by s.24(1) as

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

So far as formalities are concerned, a distinction is drawn between those treatments that are life-sustaining and those that are not. In the case of the latter, no formality is required, and s.24(3) provides that "a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms". In the case of life-sustaining treatment, however, s.25(5) and (6) provide that an advance decision is not applicable unless it is verified by a statement to the effect that it is to apply to that treatment even if life is at risk, and further that both the decision and statement must be in writing and signed by P or another person in P's presence and by P's direction, in the presence of a witness who also has signed the decision and the statement of verification. S.25(4) provides that

> "an advance decision is not applicable to the treatment in question if (a) that treatment is not the treatment specified in the advance decision, (b) any circumstances specified in the advance decision are absent, or (c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them".

The statutory requirements for advance decisions are thus fairly stringent. If, however, P has made an advance decision which is (a) valid and (b) applicable to a treatment, "the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued": s.26(1). Under s.26(4), the court has the power to make a declaration as to whether an advance decision (a) exists (b) is valid and (c) is applicable to a treatment. A valid advance decision is, however, binding in respect of the treatment to which it applies.

85. Thus, in a number of respects, including the provisions concerning advance decisions just discussed, the MCA has refined the previous law concerning the withdrawal of life-sustaining treatment. The basic principles, however, remain unchanged. In the course of the passage of the Bill through Parliament, the Minister (David Lammy MP)

confirmed that the MCA would not overturn the decision in *Bland* (HC Deb October 2004 Vol 425 Cols 23-24).

The ECHR and Human Rights Act

86. The incorporation of the European Convention for the Protection of Human Rights and Fundamental Freedoms ("ECHR") by the Human Rights Act 1998 has obliged the courts to address the question whether a declaration that the withholding or withdrawal of life-sustaining treatment was compatible with ECHR. In fact, although *Bland* was decided before the 1998 Act was passed, the House of Lords plainly had the provisions of ECHR in mind, as demonstrated by the passages from Lord Goff's speech quoted above, and after the 1998 Act was passed the courts have stated that the decision was plainly consistent with the Convention: see in particular Butler-Sloss P in *NHS Trust A v M* [2001] Fam 348.

87. The ECHR rights which fall to be considered on such an application are contained in articles 2, 3 and 8.

Article 2

88. Article 2 provides:

> "1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
>
> 2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary (a) in defence of any person from unlawful violence; (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; (c) in action lawfully taken for the purpose of quelling a riot or insurrection."

89. The European Court of Human Rights ("ECtHR") has described article 2 as "one of the most fundamental provisions of the Convention. It safeguards the right to life, without which enjoyment of any of the other rights and freedoms in the Convention is rendered nugatory" *Pretty v United Kingdom* (2002) 35 EHRR 1 para 37. As Lord Goff noted in *Bland*, however, it is not an absolute right. In *NHS Trust A v M* (supra) Butler-Sloss P, having conducted a full review of European authorities, concluded (at paras 35 and 37):

> "In a case where a responsible clinical decision is made to withhold treatment, on the grounds that it is not in the patient's best interests, and that clinical decision is made in accordance with a respect able body of medical opinion, the state's positive obligation under article 2 is, in my view, discharged …. Article 2 therefore 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, This approach is entirely in accord with the principles laid down in … Bland…"

90. Subsequently in Glass v United Kingdom [2004] Lloyd's Rep Med 76, the European Court considered an application by a mother and her severely disabled son arising out of the mother's disagreement with the clinical decisions of the doctors to prescribe diamorphine to the son and attach a "do not resuscitate" notice to his case notes. The Court ruled admissible their complaint of a breach of article 8, and subsequently upheld the complaint. A complaint under article 2 was, however, ruled inadmissible and in giving its reasons the Court, having analysed the English reported cases and observed that "it was not [the Court's] function under Article 2 to gainsay the doctors' assessment of the first applicant's condition at the time", nor their prescribed treatment, added:

> "having regard to the detailed rules and standards laid down in the domestic law and practice of the respondent State in the area under consideration, it cannot be maintained that the relevant regulatory framework discloses any shortcomings which can lay the basis of an arguable claim of a breach of the domestic authorities' obligation to protect the first applicant's right to life."

It follows, therefore, that a decision by the court, applying the principles laid down in Bland and subsequent cases, including the use of the balance sheet approach, that it would be in a patient's best interests to withhold or withdraw life-sustaining treatment does not give rise to any breach of article 2.

Article 3

91. Article 3 provides: "No one shall be subjected to torture or to inhuman or degrading treatment or punishment".

92. In Herczegfalvy v Austria (1992) 15 EHRR 437 at para 82, the European Court said that:

> "as a general rule, a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading. The court must nevertheless satisfy itself that the medical necessity has been convincingly shown to exist."

In NHS Trust A v M (supra), which concerned a patient in a PVS, Butler-Sloss P held further that an insensate patient has no feelings and no comprehension of the treatment and that, in such circumstances, article 3 did not apply. As explained by the expert evidence in the current case, medical understanding of VS has expanded significantly in the intervening ten years since that case was decided, and it may be that Butler-Sloss P's assertion would not now be applied without qualification. In non-VS cases, however, a patient may have some awareness and comprehension of the withholding and withdrawal of treatment. The impact of the withdrawal of treatment, the methods by which it is achieved, and the steps that can be taken to alleviate any suffering and distress are all part of the best interests assessment. Thus a decision by the Court, having carried out an assessment in accordance with established legal principles, that it is in the patient's best interests to withhold or withdraw treatment does not give rise to a breach of article 3.

Article 8

93. Article 8 provides:

> "1. Everyone has the right to respect for his private and family life, his home and his correspondence.
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others"

94. Personal autonomy is an important element of the Article 8(1) right. As the European Court has recently observed in *Jehovah's Witnesses of Moscow v Russia* [2011] 53 EHRR 4 (at para 136):

> "The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy. A competent adult patient is free to decide, for instance, whether or not to undergo surgery or treatment, or, by the same token, to have a blood transfusion. However, for this freedom to be meaningful, patients must have the right to make choices that accord with their own views and values, regardless of how irrational, unwise or imprudent such choices may appear to others."

95. Personal autonomy survives the onset of incapacity to consent to or refuse medical treatment. "Article 8 protects the right to personal autonomy, otherwise described as the right to physical and bodily integrity. It protects a patient's right to self-determination and an intrusion into bodily integrity must be justified under Article 8(2)": per Butler-Sloss P in NHS *Trust A v M* [2001] Fam 348 at para 41. In *Pretty v UK* [2002] 35 EHRR 1 para 65, the European Court observed:

> "The very essence of the Convention is respect for human dignity and human freedom. Without in any way 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 advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity."

However, due respect for the wishes and feelings of the patient, and for the wishes and feelings of other family members, has, of course, been a feature of the best interests assessment process since the decision in *Bland*. Thus a decision by the Court, having proper regard to the patient's personal autonomy and the expressed wishes and feelings of the patient and her family, that it would be in her best interests to withhold or withdraw treatment does not give rise to a breach of article 8.

96. Counsel for the Applicant and for Official Solicitor made various further submissions about the impact of ECHR on applications for declarations in these circumstances, including submissions continued by email after the conclusion of the hearing on the proper interpretation of the relatively old admissibility decision of the European Court in the case of *Widmer v Switzerland* (1993) Application no 20527/92. I intend no disrespect to counsel in saying that I do not think those further submissions contribute anything of value to the decision to be made in this case. In my judgment, a best interests assessment, properly conducted under English law in accordance with established principles, is fully compliant with ECHR, and it is unnecessary and inappropriate to deploy any additional arguments based on the individual articles of the Convention as a separate test of the legitimacy of the proposal to withdraw ANH. In oral submissions, Mr. Sachdeva succinctly submitted that "best interests" is a wide enough test to encompass all relevant factors in articles 2, 3 and 8. I agree.

Cases in other jurisdictions

97. In the course of the hearing, I raised with counsel whether there was any guidance on the issues arising in this case from other jurisdictions. In their final submissions, they duly drew my attention to a number of authorities from elsewhere in the world. I have considered all these authorities carefully, but ultimately concluded that they are of limited assistance to the decision I have to make and I do not propose to extend what is already a very long judgment by referring to them further, save for two American decisions cited by Miss Harry Thomas which I consider briefly below. On a general level, they demonstrate that the approach developed by the High Court and now encapsulated in the MCA is broadly in line with that adopted in many other jurisdictions. Indeed, the decision in *Bland* has had a significant influence on courts elsewhere in the world.

The legal issue between the parties

98. Nearly all of the principles recited above are not in dispute in this case. There is, however, one significant legal issue between the parties, namely whether as a matter of law the court should adopt a balance sheet approach in respect of an application concerning a patient who is in a minimally conscious state.

99. On behalf of the Official Solicitor, Miss Harry Thomas and Miss Apps argue that the balance sheet approach should not be adopted in cases where the patient is otherwise clinically stable. They argue that the balance sheet analysis cannot apply in such circumstances as it can never be in P's best interests to withhold or withdraw life-sustaining treatment. They submit that the House of Lords in *Bland* specifically rejected the weighing up the benefits and disadvantages of treatment in PVS cases and that the balance sheet approach has been confined in other cases to circumstances where the patient is very seriously ill or is at the end of their life. They point to passages in the speeches in *Bland* in which their Lordships rejected the notion that the court should weigh in the balance the patient's quality of life. In addition to the passages quoted above, they draw attention to Lord Mustill's rejection of the proposition (at page 894 D-E) that "because of incapacity or infirmity one life is intrinsically worth less than another. This is the first step on a very dangerous road indeed, and one which I am not willing to take."

100. This submission is opposed not only by the Applicant but also by the Primary Care Trust. On behalf of the PCT, Miss Dolan submits that the balance sheet approach is to be applied in all cases save for those involving PVS. She submits that a clear reading of the speeches in *Bland* demonstrates that the House envisaged that weighing up the patient's best interests should be conducted in every case save where the patient was in a PVS where the futility of treatment means that treatment had no benefit at all. In particular on this point, she cites the speech of Lord Keith in which, having referred to *Re J (A Minor) (Wardship: Medical Treatment)* he concluded that it was

> "possible to make a value judgment as to the consequences to a sensate being of in the one case withholding and in the other case administering the treatment in question. In the case of a permanently insensate being, who if continuing to live would never experience the slightest actual discomfort, it is difficult, if not impossible, to make any relevant comparison between continued existence and the absence of it."

Miss Dolan draws attention to *W Healthcare NHS Trust v H* (supra) in which the Court of Appeal approved the use of the balance sheet analysis by Coleridge J. at first instance in a case where the patient was described as being

> "…in a pitiful state. Most of her bodily functions have ceased to work because of the invidious effect of her illness, and she requires 24-hour care to enable her to survive. Her swallowing is unsafe; she is doubly incontinent; she is conscious but not much more than that; she can not speak more than the odd word; she is disorientated in time and place; and she now recognises nobody; not even those who are closest to her in her family."

The patient was not, however, in pain or particular discomfort, nor was she definitively close to death. Although not a case in which MCS was diagnosed, there are clear similarities with the present case. Miss Dolan submits that it provides clear authority for applying the balance sheet approach to MCS cases.

101. Miss Dolan submits that, whilst it is clear that the benefit of preserving of life will always weigh extremely heavily in the balance, it cannot be assumed that there will always be no relevant dis-benefit to weigh against it. Even in a clinically stable patient there must be room for any relevant psychological and emotional aspects of their position to be taken into account as part of the balancing exercise. She further argues that the fact that the balance is most likely to come down in favour of preserving life in a MCS patient whose only medical treatment need is for ANH is not grounds for saying that a balance between factors in support of and against providing such treatment need not be struck in such cases. To do away with the balancing exercise and balance sheet would be to disregard the requirement of s.4(2) MCA that consideration be given to "all of the relevant circumstances" and would also disregard s.4(6) MCA which requires consideration of those matters of import to P or that P would be likely to consider if he could do so, when coming to any best interests decision. In addition, she points out that the Official Solicitor's proposal that the use of the balance sheet analysis should depend on whether or not the patient was clinically stable merely begs the question of what "clinical stability" means. Depending on the particular circumstances, there could be a multitude of possible indicators of clinical stability, including absence of acute illness, absence of acute

symptoms, presence of vital signs, absence of pain, absence of psychiatric disorder or acute psychological problems, and responsiveness to treatment. Assessing whether a patient is clinically stable would itself involve weighing up a variety of factors. Miss Dolan submits that if it were to be accepted that the presence of an acute single physical symptom, such as pain or discomfort, could indicate that a patient was not clinically stable, then, when considering best interests, there could be no rationale for not also weighing up the intermittent pains and discomforts of normal everyday life and/or those discomforts associated with the restriction of movement that will usually accompany the chronic disability of an MCS patient. For these reasons, the PCT, supported on this point by the Applicant, submits that the Official Solicitor's suggested approach is wrong in law and unworkable in practice.

102. On this point I am wholly unpersuaded by the Official Solicitor's argument and fully accept the submissions advanced by Miss Dolan on behalf of the PCT. There is, in my judgment, no rationale for extending the approach adopted by the House of Lords in *Bland* to non-VS cases. Lord Goff specifically distinguished between cases in which, having regard to all the circumstances, it may not be in the patient's best interests to continue treatment and cases in which a patient was permanently insensate and thus unable to benefit at all from the treatment. Crucially Lord Goff observed: "In both classes of case, the decision whether or not to withhold treatment must be made in the best interests of the patient. In the first class, however, the decision has to be made by weighing the relevant considerations." There is no justification for introducing a requirement of clinical instability before embarking on a balance sheet analysis in MCS cases. To do so would introduce an impermissible gloss on the best interests test, and undermine the clear requirement laid down in s. 4 of the MCA to consider all the relevant circumstances when determining best interests. It would also lead to lengthy satellite argument as to the meaning of "clinical stability" and the diversion of legal and medical resources into determining that issue.

103. On the other hand, the fact that a patient is demonstrating what may be seen as the components of clinical stability is unquestionably an important factor to be taken into account in the balance sheet analysis itself. For example the fact that a patient is not experiencing undue pain or discomfort, is not suffering from any acute illnesses, and seems psychologically settled, will be significant factors to take into account. The longer the patient has demonstrated these symptoms, the greater the period of clinical stability and the more weight to be attached to these factors in the balancing exercise.

THE EVIDENCE

104. The bundles of documents filed for the hearing included statements from family members, staff working at the care home, reports from clinicians who treated M in the initial stages of her hospitalisation, Professor Andrews, Mr. Badwan, Miss Gill-Thwaites, the clinicians at the hospital in Putney, and Professor Turner-Stokes, and extracts from the extensive medical and care records. Oral evidence was given by two members of the family, ten members of staff at the care home, Miss Gill-Thwaites, Professor Turner-Stokes and Mr Badwan. A bundle of research articles was produced incorporating material cited in the experts' evidence.

(1) The Family's evidence

105. A number of statements were put before the court from several members of the family, namely W (M’s mother), B (her sister and litigation friend), S (her partner) B’s younger son and S’s mother. Sadly since the start of these proceedings W has developed dementia and S’s mother has died. I have read and taken into consideration all the statements by family members. Oral evidence on behalf of the family was given by B and S.

B

106. B and M have always been close. The sisters are two years apart, went to the same school, and on leaving on school both took up the job of hairdressing together. They lived near to each other in the same town, saw each other at least once or twice a week, went shopping together, took holidays together and spent Christmases together. M has no children but had a very close relationship with P’s two sons.

107. In her oral evidence, B spoke very movingly about her sister. She described her as tall, dark, slim, someone who loved life, her holidays, her home, her dog. She described how M was always up early at five o’clock in the morning, always holding the view that this was the best part of the day. She was fun-loving, considerate, kind and caring. She liked to gossip but was never malicious. B described how M had firm views on many things. Both of them had been very close to their maternal grandmother who in her nineties had gone to live in a nursing home where her health and capacity had gradually declined. B recounted that M had always said that, if she was in danger of going into residential home, she would rather shorten her life by ten years rather than have someone look after her. B told me that M did not wish to be looked after in the way that her grandmother had been. She was fiercely independent and according to B would have hated to have been looked after. B described how M had said similar things when their father became ill a few years later and had to go into a care home and also during the time of the publicity about the Tony Bland case. B remarked ruefully that this is not something that you think is going to happen to you.

108. B stressed that she could not argue with the quality of care that M has received in her nursing home. Her argument was that she knew that M would not have wanted to live like this. B spoke how M was unable to move, speak or communicate with anyone. “Not to be able to communicate with anyone is inconceivable.” She accepted that M was able to open her eyes but asked: “Why is that meaningful”?

109. B said that various doctors had said that M should not be treated by antibiotics and she was unhappy on reading the records in the course of preparing for this case that M had been treated in this way. S had asked her whether he thought that M should be given a flu jab. B has said that she did not think that this was a good idea. She thought that they should let nature take its course.

110. Initially when M became ill, B visited her every day and spent much of the day there. When she came out of the coma on 30 May 2003, B and other family members were hoping that she was going to wake up but gradually the realisation sank in that this was what it was going to be like until she died. M was moved to the rehabilitation unit in the second hospital where she remained for over four years. B said that she had resisted the suggestion initially that M should be moved to a nursing or care home. She and other family members wanted the doctors to try everything they could

to bring about a recovery. They thought that if she moved to a nursing home she would never get rehabilitated and there would be no chance of recovery. In addition, when B visited a number of nursing homes in the area, she was unhappy at the thought that her sister should move to anywhere like that. She couldn't find any suitable place for her to go. She described some of the places she visited as "horrendous".

111. B described how gradually weeks turned into months, months into years. S had kept saying we have got to give her every chance. B used to go and visit on a regular basis and do things for M – cut her hair, cut her nails, take clothes in and talk to her. She then decided that it would be like torture telling her things about what she had done which M was no longer able to do. She decided that she would rather not tell her about these things.

112. In oral evidence, B asked rhetorically: "What can she possibly get out of life? No pleasure. The daily routine of being got out of bed, put back, dressed, doubly incontinent. It's not a life, it's an existence and I know she wouldn't want it. It pains me every time to see her in bed, in the chair, she doesn't resemble anything she used to look like." B insisted that she was pursuing this application out of love for her sister. "It's solely for my sister. It would be easy to walk away but I'm here because I think I'm doing the right thing. I know that's what she wanted in her hearts of hearts".

113. On behalf of the family, Mr Sachdeva asked B about the number of responses reported by members of the care staff and summarised below. B said that she had not really seen any of them – no smiling, no opening eyes in response to anything, nor any tracking with her eyes, no laughter or any response to music. She accepted that on occasion M had appeared to smile but did not think that this was necessarily a response to anything. She described how she had asked M in the past to give her a smile and her mouth had on occasions moved a little. B has not done that recently, because in her words, M "has got nothing to smile about". B was sceptical about whether M had any capacity to speak. She pointed out that you need your tongue to speak and that M has no control of her tongue. She accepted that M had a number of different noises that she makes and it might be that a different noise is made for a different need, but B was unable to differentiate this because she does not provide care for her. She acknowledged that M does make different noises at different levels of volume and B was unable to say if the noise reflected any particular need. She asked: "how can you tell someone's mood when they have got a severe brain injury?"

114. When cross examined about the results of the SMART assessment, B said that she did not agree that M had the abilities identified in the assessment but added: "well, I didn't really know she did". She didn't deny that M was capable of the movements described in the assessment but queried whether these indicated that she had any real capacity. She was concerned that there was a risk that M was being used as an experiment. B said that in her opinion M is not responding at all. There might be a few responses but "they're meaningless". She was asked specifically about the evidence that M had responded to the Adele song "Someone like You". She said: "anyone would respond to it – it's that type of song".

115. B has now stopped talking to M about her family. "To be quite honest I don't really talk to her, I go in and sit. I don't stay for that long. I go in to see what I have to do –

check her clothes, check if she needs anything, if her nails need cutting etc". These days she is probably visiting every three or four weeks. In cross-examination, M acknowledged that she had stopped taking in photographs of the family. She acknowledged that members of staff had said that family photographs would help M, but she thought that M might be upset at seeing photographs.

116. Questioned by me, B agreed that she was influenced by what she remembered of how her sister had been before she became ill. She thought that whatever steps may be taken would not bring her back to anything like how she was. B was unable to accept that taking M out would be a source of pleasure. She thought that M would not want to be taken out in her condition. "She can't enjoy things like she used to do, how can being taken out change her condition?" B added that she could not see the point of giving M's antibiotics "to bring her round for years of more suffering for this – I would rather let nature take its course". B said that she would rather M was just left quiet and comfortable. She did not want her to have endured for years and years. "I want her to be allowed to die in peace".

<u>S</u>

117. B's evidence was supported and supplemented by that of M's long-term partner S, who spoke with obvious devotion and sincerity about his long relationship with M and the devastating impact of her illness upon their lives.

118. S and M met in 1982 and had been in a relationship ever since. They have lived together in a number of properties and although they have never married, their relationship has always been close and solid. He described M as a strong-willed person who was not one to shy away from things she believed in. "She'd stand up for herself and for me". S described how she had cared for him when he had been quite ill some years ago. He described her as "my rock". He said that she was someone who was pretty focused on what she wanted out of life – someone who knew her own mind. She was very house-proud and was not one for sitting around – the sort of person who'd look after other people before herself.

119. S described in moving terms the events of the 17 and 18 February 2003 when M became suddenly ill and was admitted to hospital. Thereafter S said that he was determined that M was going to get better – "I said: She is all I have got". He said that he felt that they, by which he means the doctors, were giving up on her and he wanted to keep fighting. He said that it took him a long time to accept what the doctors were saying about her. He was always against her going into a nursing home because of what she had said to him following the experiences with her grandmother and father. He said that at the time of her father's illness, M had said: "don't ever put me in a place like this". She said that she wanted to "be off quick" and not dependent on others. S said: "I think that she would be horrified that she was carrying on in this undignified manner. She was a very proud person and very conscious of how she presented herself. She wouldn't want to continue with this burdensome life with a lack of dignity."

120. Mr Sachdeva asked S about the observations made by care staff as to M's responsiveness. S said that he was only able to speak from his own perspective and he could not see the things that the carers saw. When he visits her, S still likes to talk to her and play music to her but he said that he was not as vigorous as he had been at

trying to get a response. He said that he had never seen her respond to music. He said that if he repeatedly asked M to open her eyes, eventually she might do so. S described how this lifted his spirits temporarily but afterwards there was no further response.

121. S described how he and other family members had concluded that what M would have wanted was to "put an end to her suffering". He stressed that he was not seeking to alleviate his own distress. "It's not about us. We're irrelevant. I could only speak up for her, knowing her views and opinions. We're her voice."

(2) The Care Home staff

122. The care home, which I visited during the course of the hearing, was constructed about five years ago. It consists of four units designed to meet patients with varying needs. The unit where M lives can accommodate up to ten residents and is designed for people with severe disabilities. Each has their own bedroom. There are two lounges, a garden, and a sensory room, known as the "snoozeroom" or "snoozlum", a small room which can accommodate one or two residents in which there is music and special lighting and other things to provide a sensory experience for the residents.

123. The care team at the home includes a number of care staff, skills workers and physiotherapists and physiotherapy assistants. Ten members of staff at the care home gave evidence before me at the hearing. I shall now summarise their evidence in the order in which they were called.

Nurse O

124. Nurse O is a senior nurse and in charge of all the nursing services for the unit at the care home. She described M's usual daily routine. M wakes up early about 5am at which point she is often very vocal. She is usually washed and changed by 6am. Nurse O described how M's carers talked to her, telling her what they are going to do and speak to her throughout the process. M receives early morning medication between 6.30 and 7. Throughout the day, and night, M is repositioned every three to four hours to make her more comfortable and to avoid pressure sores. During the day, she might spend some time in her room or in the small lounge with her carer and one or two other residents, either with the television on or off. Sometimes she goes into the snoozeroom. On occasions, singers or other entertainers come to entertain the residents. M is fed by a gastrostomy tube or Peg tube. The tube is changed every three months, a process that takes about five minutes during which no pain relief is required.

125. Nurse O said that M is generally in good health. Although the GP visits the home once a week, he rarely sees M. O described M as medically very stable. In the last three years, M has had very little illness. She had an ear infection in May 2008 for which she received antibiotics and a chest infection in October 2009 for which she was again prescribed antibiotics. In addition she has been prescribed antibiotic cream for various problems.

126. Nurse O described how M "makes sounds which I think is her way of telling us she wants us to do something, whether she is content or upset." She said that, when M is settled, she is usually very quiet, making a low sound a bit like a hum. This is very

different from the noise that M makes when she wants to let the care staff know that something needs doing, for example, her pad needs changing. Nurse O described how if one looks directly at M or comes within her line of sight, or says something to her, she will usually screw up her eyes. However, after a short while, she will open her left eye and look again. Nurse O describes how she has been present when staff gossip when they are with M and how M will respond by opening her left eye and sometimes both eyes and definitely look at the members of staff. Generally, according to Nurse O, if you focus on M and she sees you she will close her eyes. Also, if you mention that she has her eyes open, she will probably close them. But if no-one draws attention to the fact that her eyes are open, she tends to keep them open for longer and appears to look round at things.

127. Nurse O thinks that M is sometimes aware of different people. At other times, she shows no such awareness. She described seeing M move her hands to more upbeat music, usually from the 70s or 80s with a fast rhythm. In cross-examination she described how she has observed M tap her wrist on her hand in a way that appears to be in time with the music. She said that she has also seen M appear to smile with the more upbeat music – “it is a flicker of a small smile, her mouth will turn up, and to me it looks like a definite smile”.

128. Nurse O describes how M responds to people talking about hair. There have been members of staff with what Nurse O described as “outlandish” hair colours which, if commented upon, will lead to M opening her eyes and looking at the person concerned. Nurse O described how, on a number of occasions, she had asked M what she thought of so-and-so’s hair, to which M has responded by opening her eyes and looking at the person’s hair. In oral evidence, Nurse O also described how she had seen M respond to the television. For example, shortly before O gave evidence, she had seen M apparently watching the television coverage of tennis at Wimbledon.

129. Nurse O described how it is clear that S is still suffering as a consequence at what has happened to M. She said that he is very distressed and sometimes seems close to tears. He is quiet and very polite to members of staff but Nurse O told the court that she gets the impression that he wants to be left alone with M. On a few occasions, she has entered the room when S has been there and she has seen him sat with his head on M’s lap, clearly very distressed. She has never heard S speak to M. Nurse O described how S is very devoted to M and protective of her. He doesn’t want any photographs taken of her and became upset when he saw a photograph in her room of an occasion when owls were brought to the unit and shown to M and the other residents. Nurse O expressed the wish, that if the application to withdraw ANH is refused, she would wish to see changes in M’s management in the care home. In particular, she told the court that the staff would like to have some photographs of M or other things to personalise her room.

130. Following the best interests meeting in December 2010, it was agreed that M would be taken out for three trips from the care home in the following spring. Nurse O was assigned to the task of taking her out with another member of staff, and described the three visits in her statement. On the first visit on 11 April, she described how they had visited a lake and how she had seen M look at her and her colleague and then appeared to be looking up beyond them at some trees for at least a minute. When some ducks came up on the lake she turned her head to the right to see them swimming. Nurse O described her eyes as “clearly moving and tracking.” Nurse O

estimated that M had her eyes open for two to three minutes and possibly longer. During that time, M was clearly relaxed with her hands by her waist instead of in their usual position held up by her chin. In the course of that first outing, Nurse O held M's hand in the bus on the journey and when they were walking to and from the lake. During these times she noticed it was quite flaccid. When the wind blew into their faces, however, she noticed how M gripped her hand more tightly. Nurse O made similar observations on the second outing. When M's wheelchair was being pushed across a rough path, M became tense and pulled her arms up under her chin. Later, when they got to a smooth path, M became relaxed In addition, Nurse O observed how at one point M turned her head towards the sun so it shone in her face. While they were sitting by the lake, she had her left eye open for much of the time. On the third outing, Nurse O observed how M flinched in reaction to a cold breeze. On this occasion, M's level of response was not the same as had been shown in the first two visits.

131. After these three trial visits, it was agreed that further visits could be undertaken. Nurse O described similar responses from M during some of these visits. In particular, on 28 June, when care staff remarked how there was a fireman in the farmyard they were visiting, she briefly opened her left eye. Nurse O continued: "as we returned to the minibus, we again started talking about the fireman and commented on the fact that he had gone. At this point M opened both her eyes very wide for about thirty seconds. We teased her that we would not tell S that she had been looking at fireman, at which M opened her eyes and made a groaning sound as if she was trying to communicate something." Nurse O's evidence about these outings clearly demonstrates that M has some awareness about her environment. It is Nurse O's view that M should continue to go on outings to a variety of locations.

132. Since January 2011, members of staff have been asked to fill in activity/response sheets recording full observations of responses observed in M. In her statement, Nurse O stated that she was aware that there could be a concern that staff might say things with a view to try to influence the outcome of these proceedings. For that reason, she says that she has explained to all staff that they must record their observations accurately as possible and understand that they might have to give evidence on oath about them. Nurse O accepted in answer to questions from Mr Sachdeva that there is a degree of subjectivity in the observations of M's responsiveness. She accepted that the response/activity sheets would tend to cite positive sightings of responses and that a lack of responsiveness would not necessarily be recorded. She added, however, that she and other members of staff are present for longer than B or S and therefore potentially see more responses than do members of the family.

133. Nurse O expressed the view that since Ms Gill-Thwaites' visits and the second SMART assessment (considered below), M has become more aware. Before those visits, her eyes were closed for the majority of the time whereas now they are open more frequently. Nurse O accepted that this was just an impression from which she had seen and from what members of staff were telling her. Along with other members of staff, she accepted that she had no training in neurological observation.

Skills worker H

134. Skills Worker H is a life skills co-ordinator at the care home where she works with a team of three others. She works four ten-hour shifts a week. Her job involves organising and facilitating activities for the residents which take place both in the care home and out in the community. She sees it as her responsibility to try to ensure that the residents are able to do what they want and she organises day trips outings and holidays as well as time in the snoozeroom and in-house entertainment.

135. H has worked with M for about the last three years. Amongst her tasks is to manicure M's nails which she does every fortnight. When she does this, she also gives M a hand massage. She has noticed that M's arms relax during the message. While H is massaging M's hands, M will usually peek at her through her left eye. H describes how she often says things to her such as "you're peeping", but if M catches her looking at her, she will shut her eyes and keep them very tightly closed.

136. H describes that, when M is taken to the snoozeroom, she generally appears to relax which is demonstrated by her lowering her arms. H describes how M reacts in distinctive and consistent ways to different music. About two years ago, H observed M becoming very upset when a particular track – a Lionel Richie love song – was being played. When the tracks came to an end, H observed that M stopped crying quite suddenly.

137. H reads to M about once a week. She has observed that when she does this, M is usually very quiet and even if she is a little bit more vocal at the start of the reading, she usually quietens down as H reads to her. While reading, H occasionally makes comments to M about the story. On a recent occasion, when she started reading, M started making a louder and higher-pitched noise which H interpreted as indicating that she did not want her to read. She therefore stopped and switched on the television whereupon M became quiet. H also described how on 7 April 2011, during a visit by an in-house entertainer, M became noticeably more relaxed, and kept opening her left eye fully and glancing around the room.

138. H accompanied M with Nurse O on the outings organised during Spring 2011. She confirmed a number of the observations seen by Nurse O - for example, she describes how M responded in the stiff breeze. On one occasion, when they were walking past the lake, she said to M: "open your eyes – it is a lovely lake". At this, M appeared to look at the lake by turning her head to the right. H said that she appeared to look for quite a while before she moved her head back to its usual position. On the occasion of the second visit, H described how, while they walked around the lake, M turned her head to the direction of the sun and seemed to "be really pushing her face towards the sun". H reiterated this in cross-examination and demonstrated how M had pushed her face upwards in the direction of the sun and held it there for some time. H gave a similar account to that provided by Nurse O about the reaction showed by M during a subsequent outing to the conversation concerning a fireman.

Care Worker C

139. Care Worker C has worked as a care assistant at the nursing home since July 2008 and has worked with M ever since. She works four twelve-hour shifts a week and will spend one or two shifts per week with M depending on how the rota is organised. C described how her usual experience of working with M is that if she sees you watching her she will close her eyes. Very rarely does she look at her with both eyes

open. C has noticed that if you have a gossip in M's presence, she will open her eye or eyes and look at you. C has never seen M smile, nor respond to the television. In cross-examination, C accepted that she found it difficult to say if M gets any pleasure from anything.

140. C described how M moans when she is wet or after her bowels have opened. She described it as a very loud moan that can be heard throughout the unit. It is C's view that M is trying to let them know she needs changing. C said that once M has been attended to, she usually stops the moaning. C described how M quite often moans loudly at night. Once again, she will usually settle after she has been attended to but occasionally the moaning continues. In cross-examination, she described how M tended to get quite vocal at the beginning of the morning.

141. On one occasion in the summer of 2010, when M was in the living room, an Elvis Presley ballad was played on the television. C recalled looking at M and seeing tears rolling down her cheeks. That is the only occasion when she has seen M cry in response to music and thereafter she has taken care to avoid playing any Elvis songs. C described how on two occasions she has seen M cry after S has left the bedroom following a visit. On both occasions, M made no noise but she can see tears rolling down her cheeks.

142. C gave evidence about how she had heard M talk on two different occasions. On the first occasion, whilst she and another carer were working together and were about to turn M over to change her, she said "bloody hell". More recently on 12 April 2011, when she went in to see M early in the morning, she noticed that M was staring at her and she said "Good Morning" to which M replied, "what". C says that she repeated "Good Morning" to which M said "what". C then asked M if she was hot to which M replied "yes". C then asked her if she wanted to take her blankets off to which M replied "no". At this point, according to C, another carer came into the room called X. At this point, C crouched down to look directly at M and said "Are you going to say good morning to X?" M replied "morning". At this point, according to C, M had both her eyes open. C says that she is absolutely clear that M spoke these words which were very distinct and clear. Cross-examined by Mr Sachdeva, C insisted that it was not possible that she had misheard what M had said. She was quite taken aback because this had never happened before. This is the only occasion on which she has heard M apparently speak. C said that she had never seen M smile. In cross-examination, she said that it was "really hard" to say if M took pleasure in anything.

Skills Worker R

143. Skills Worker R has worked at the care home since May 2008. Whilst she does not do many activities with M, she says that she sees her nearly every occasion that she enters the unit. R has noticed that, when she is bantering with her about men, M will respond by being more vocal, making a louder noise and changing her facial expression into what seems like a smile. In oral evidence, R said that if she says something like "how come you get the most handsome man", M may respond by opening her mouth wider in a way which thinks is a smile. R has seen M in the snoozeroom which she regards as a positive experience for her. M smiled during some songs but not others. R remembers M smiling at the song "Tiger Feet" by the group Mud and making more hand movements during that track.

Care Worker L

144. Care Worker L has worked at the care home for five years, save for a break of fifteen months. She is M's key worker which requires her to take responsibility for certain practical arrangements about M's care. She works two shifts a week and calculates that she spends three to four shifts a month with M. Her role is that of a hands-on care worker, getting M up and putting her to bed, turning her whilst in bed, showering and changing her.

145. She said that, in the years that she has worked with M, she has seen no real change in her behaviour. She has seen M pull a lot of different faces but has never seen M smile. Like other staff members, Care Worker L judges her to be comfortable when she seems relaxed when her arms have dropped away from her neck and her hands have loosened. She makes a quiet low moan when she is apparently comfortable. Care Worker L regards it as a sign of discomfort when M changes the volume and pitch of the noise, so that, with experience, one learns to judge whether or not her moaning is an indication of discomfort. When distressed, M's arms become very rigid and she holds them under her chin. Care Worker L describes how some days M's eyes are squeezed close together whereas on other days they are open. Like other members of staff, she has noticed that if she speaks to M with her eyes open she will usually squeeze them shut again.

146. Care Worker L describes a different reaction in M on 1 May 2011. At around 11.30 that morning she entered M's room where M was lying on her back in bed. She noticed that M had one eye open and one eye shut. Normally M would shut her eyes when Care Worker L entered the room, but on this occasion she kept them open, so L bent down and looked at M at eye level, face to face. M appeared to focus on her face and Care Worker L spoke to her whilst looking into her eyes. She told her things such as the day of the week, the year, and what the weather was like. Care Worker L formed the view that M was listening to her. She had not seen that level of response in M before. Normally she would scrunch up her eyes but on this occasion, according to L, "she seemed to be really looking at me – that's why I remember it". Cross-examined by Mr Sachdeva, L described her memory of the incident of 1 May as clear. It was out of the ordinary for M. As she looked at her, she seemed to be really focused on her face. L does not know whether M was listening to her but she seemed to be doing so.

147. On 21 June 2011, Care Worker L observed M in the lounge, apparently focusing on the tennis on the television. When a nurse approached M and asked if she liked tennis, M nodded her head as if to indicate yes. In cross-examination, carer L said she was "100% sure" that M had nodded when asked if she liked tennis.

148. Carer L has described how M has good days and bad days and estimates that the good days are about three out of ten. She thought that M was in pain, discomfort or distress for about 30% of the time.

Physio L

149. Physio L is a general physiotherapist who graduated in 2009 and now works full time at the care home where he is supported by two assistants who are not qualified but carry out tasks such as abdominal massage and daily stretching exercises.

150. He described M as capable of reflexive movement. She can close her eyes by squeezing them tightly together. She rarely opens her right eye but when relaxed can open her left eye, and can open it when spoken although not consistently to command. Physio L described how M can open and close her mouth. Physio L described that M has some degree of neck flexion. Her neck is left side flexed and rotated to the right. She has some limited right flexion in her neck which is naturally protracted. If she is startled she will usually protract her shoulders. She naturally protracts her arms forward. Her arms are also internally rotated and turned so that they are held across the top of her chest with her hands under or next to the chin. She has a full range of passive movements in her wrists, but normally only uses a small amount of the wrist movement turning her hands upwards. When she is in a chair, she will normally be flexed to the side. She does sometimes flex her trunk when apparently watching T.V. There is very little movement in her hips. She has some flexion and extension in her knees but passive movement of her ankles and feet are limited. Physiotherapy has produced some slight improvement in some of these movements and on occasions M has relaxed appropriately to massage. Physio L believes that physiotherapy is a positive experience for M.

151. It is Physio L's view that M is usually free of pain, although on occasions she displays what he describes as "a pain pattern", meaning a pattern that he recognises from treating other patients as suggestive of pain. In cross-examination, Physio L accepted that he had no specific expertise in detecting pain.

152. When he first met M she was sitting in her chair and responded positively to him. He described how she had opened her left eye, then her right eye, then smiled and raised her arms up so that her face was hidden. Then she lowered her arms, still smiling but with her eyes closed, then she had opened her eyes and raised her arms again. She maintained the smile throughout the meeting. Over the following week, physio L describes how M seemed to get more used to her, still smiling although her reactions were not as extreme. Thereafter, her response to him has dropped away somewhat, although, when he speaks to her, she will usually open her left eye and then both eyes again to have a look and smile. When he is around, she will sometimes open one or both eyes and look at him. Physio L has observed M tracking her and others with her left eye, although he has not seen her do that with her right eye.

153. On one occasion, in 2010, Physio L said "hello" to M. Initially he had no response but when he repeated it M clearly said "hello". He asked her twice how she was and got no response, but when he asked her a third time, she replied: "Where am I?" L says about this incident: "the speech was muffled but it was easy to understand, the word "where" was very clear although the further two words were more muffled." In cross-examination, Physio L said that he was "one hundred per cent confident" that M said "where am I?" Since this incident, M has vocalised on a number of occasions when seeing him although she has not said any words. The vocalisation is either a moan or a groan.

154. Physio L says that he has observed M crying on two occasions. On the first occasion she was lying in bed with her bedroom door open and she appeared to be moaning and sobbing. On the second occasion, she was in her hydrotilt chair in the living room, listening to music with carers present. It seems from his evidence that Physio L may not have been present throughout this incident and was to some extent reporting hearsay accounts. When an Elvis track called "You were always on my mind" was

played, M started to cry and continued to do so about ten seconds after the record stopped playing. When the song was played again, M started to cry again and when the track was paused she stopped crying. According to his statement, staff resumed playing the song at which point M started crying again, but when the track was stopped she stopped crying within a few seconds. Physio L describes that the carers then played a few different Elvis tracks to which M showed no reaction but when they again played "You were always on my mind" she resumed crying. On a different occasion, Physio L observed M tapping her hands while music was being played.

155. In oral evidence, Physio L confirmed that he has seen M smile on a number of occasions. He describes this as increasing tone in the face, her mouth opens, her lips elongate as to show more teeth and her mouth sometimes opens. He has witnessed her smile during some music, for example, Elvis and UB40 records, and also while watching television programmes. In cross-examination by Mr Sachdeva, Physio L conceded that what he saw as "a smile" could be an extension of a grimace.

156. Having read the medical records, Physio L commented that M was nursed in bed, and not regularly placed in a chair, for some considerable time in the early years after her acute illness. He thinks that she has not had as much therapeutic input as she could have had, and he thinks it would be "good to see if we can improve her quality of life".

Physio Assistant S

157. Physio Assistant S helps Physio L with physiotherapy in the care home. She started working in the care home initially as a care assistant but since the end of 2008 has worked in her capacity as physiotherapy assistant. She sees M on a daily basis when she is at work. She speaks to her and can tell by her response how she is feeling. She says that, if M is comfortable, she will make a sort of humming noise when she moans. On the occasions when she is uncomfortable, she will make a different sound, a slightly higher pitched moan. When she makes this sound, Physio Assistant S says that there is always a reason for it, usually because she needs some form of personal care such as her pad changing. Physio Assistant S says that "she knows when M is happy she appears to smile".

158. Physio Assistant S says that there is a definite movement of the sides of her mouth and lips when she appears to smile. Physio Assistant S describes how when M is unhappy or distressed she will usually screw her eyes up and her lips and will bring her clenched fists under her chin. When Physio Assistant S is doing some passive movements on her, M sometimes pulls her arm into her body as if to say, "don't touch me today".

159. Physio Assistant S sometimes cleaned M's teeth. When she does this she asks M to stick her tongue out which M does on the majority of occasions, although it sometimes takes a few requests to achieve this. She has in the past asked M to squeeze her finger to indicate whether she wants something. Some times she does respond in this way, but on other occasions she does not.

160. Physio Assistant S describes M as having a different relationship with other carers. For example, she had a particular relationship with a former colleague, T, and

whenever she heard T's voice, M would "invariably smile". When T was in the room, and M opened her eyes, she would always look at T.

161. Physio Assistant S describes how on one occasion one of the nurses had been to a wedding in Las Vegas and had brought back a DVD of the occasion which she had shown in the lounge. M was present there while it was being played and got quite emotional, making a crying sound, although she wasn't shedding any tears. As she was distressed, they stopped playing the DVD whereupon M settled again.

Care Worker K

162. Care Worker K is one of the carers on M's units and has worked at the care home since June 2008. In her statement, K describes how she regularly takes M to the snoozeroom when she has noticed that M's hands will gradually drop down her chest, showing that she is relaxed. Sometimes in the snoozeroom, M will appear to tap her wrist to the music. K has only seen her do this action when music is playing. She was unable to say whether or not M was beating time to the music but it seems to her that was what was happening. K has also heard M murmur to music. K described how M seems to relax in the snoozeroom and look at the lights that are flashing on the walls.

163. K gave evidence about a particular incident on 15 April. M was sitting in the lounge and the music channel was on the television. The well-known track by Adele called "Someone like You" was playing. M was vocal during the song but, towards the end of the song, she started to cry, making what K describes as a "piercing, squealing sound" at a higher pitch and louder than normal. K recalled that when the song had been playing earlier that morning while she and another carer were giving M a shower, she had been "very vocal" on that occasion as well. K said that whether it was the words, music or the voice, she did think that there was something in the Adele song to which M was responding. On 6 May 2011, K observed M making a similar sound when a track by Rod Stewart was played. She screamed and K saw her eyes fill with tears. K took the song off and played another one. When M had stopped crying, she put the Rod Stewart song back on again and M started crying again. K commented: "I am absolutely sure it was a scream and can confirm that M's eyes were full of tears and they were running down her face. It was similar to the piercing squeal that I heard from her on 15 April. It was the most extreme response I have ever witnessed from M".

164. K has seen other examples of M responsive behaviour. She described how, if M is in discomfort, or does not want to be touched, she will screw up her face and appear more tense. She said the sounds made by M indicate whether or not she is in pain or distressed. K describes how M seems to enjoy being taken into the garden where she seems relaxed if it is warm weather. She described how she has been in M's room after S has left and has seen tears rolling down M's cheeks which she has washed from her face. In oral evidence, K described how M seemed to respond to a former colleague T who used to tell her to put her arms by her side and she would respond.

165. K described how when she recently returned from holiday, she told M that she had "burnt my boobies". In response to this comment, M had made a sort of smile in that the corner of her mouth went up and the top lips moved to show her teeth.

Manager W

166. W has been the manager of the care home for about nine months and was previously employed there as the clinical nurse manager. She was never allocated as M's nurse, but has had more contact with her since she became manager. She described how M's room is barely decorated. Unlike nearly all the other residents, M has no photographs and very few possessions in her room. Manager W thinks that it would be to her advantage for her surrounding to be made more attractive by photographs and other personal belongings. Normally, the care home has a book with photographs and pieces about each resident, but S has refused to permit this in M's case.

167. Manager W records how she has heard about S' visits during which he spends time on his own with M in her room. Staff have told her about the occasions they have observed S sitting with his head in M's lap. She described this as "one of the worst cases of continuing bereavement I have seen and it is sadly very clear that S has not been able to come to terms with the loss of how M used to be".

168. If ANH is not withdrawn, Manager W would wish to be allowed to give M a wider experience of activities and more stimulation. Hitherto, it has been difficult to do this because of opposition from the family. She describes that at the best interests meeting in December 2010, S indicated that he did not want anybody from the outside world seeing M. Manager W understands this view because she knows from her experience that, sadly, some people in the wider community can be insensitive or even cruel in their treatment of disabled people. Despite this, she believes that they will be able to offer M a more positive life if they were allowed to take her out for other activities.

<u>Care worker W</u>

169. Care Worker W has worked as a carer for over 20 years, and has worked on M's unit for the last two years. She gave a similar picture of M's condition and responsiveness as provided by other members of staff at the home. She told the court that, if M is settled, she does not screw her face up. If agitated or frustrated, she will have her arms and hands up by her face, but when settled they will be lower down her chest. Like other staff, Care Worker W said that she has noticed that the noises made by M vary depending on her needs. If she is cold, she will make a low monotone, whereas if her pad needs changing, the noise has a higher pitch. This occurs at all hours, but is particularly noticeable at night. On two occasions, care worker W has heard M make noises in the snoozeroom, as if going along with the music from the CD player. The sound is not necessarily in tune, but seems to rise and fall in line with the music. She has also seen M tap her arm to the music, perhaps ten or fifteen times, in particular when an up-tempo song is being played. She has seen M look at the pattern of the lights on the wall in the snoozeroom. Usually it is her left eye that is opened, but she can open both eyes. She has seen this on about 90% of the occasions she has seen M in the snoozeroom. Care Worker W has also seen M open one or both eyes on the lounge on about 80% of the days she has seen her there, although not for the whole of the time that she is there on that day. She described how M will screw her eyes up if you say to her: "I can see you peeping".

170. Care Worker W was also present on the occasion when M apparently cried when the Elvis song "You were always on my mind" was playing. When she asked if she was ok, M started sobbing. Care Worker W gave her a hug. When the song stopped playing, M stopped crying. When Physio L came in, the staff explained what had happened, and he played it again, and M started to sob again. On the same day,

according to Care Worker W's oral evidence (and recorded in the care home records, although not mentioned in her statement), she observed M apparently mouthing words while another song was playing ("Green, green grass of home").

171. Care Worker W gave evidence of how M behaved in what she described as a "flirtatious" manner when Mr. Badwan visited. When he asked her, taking his cue from a song that was being played: "Are you a New York lady?" she pulled her arms up, pulled up her shoulders, closed her eyes, smiled, and made a two-tone noise. She has seen her behave in a similar way towards Physio L. According to Care Worker W, M seems to turn her head more and listen if a man is speaking. Care Worker W described how Mr. Badwan clapped his hands without warning and M jumped. Then when he told her that he was going to clap and did it again, she did not jump.

172. Asked by Mr. Sachdeva about her observations, Care Worker W said that it was like having a baby in that she has learned to interpret M's behaviour over time, although Care Worker W confirmed that, like all the other care home witnesses, she had no training in neurological observation.

Conclusions about evidence of care home staff

173. Mr. Sachdeva asked all of the staff at the care home who gave evidence whether they thought ANH should be withdrawn from M. The majority said they did not think that it should be withdrawn, and the others said that they preferred not to express an opinion. It was not suggested that the views of the majority had influenced the evidence they had given. I found all of the staff from the care home who gave evidence to be honest and reliable witnesses who were manifestly endeavouring to give accurate evidence. Their devotion to their work was obvious. Whilst there may have been some instances of over-interpretation in a few of their observations, overall I accept the picture given by this evidence as an accurate portrayal of M's condition and behaviour.

174. I draw the following conclusions from that evidence.

(1) M has some awareness of self (demonstrated, for example, by her tendency to close her eyes tightly when spoken to, by her occasional responses to command, the fact that she relaxes when massaged, and her distress after S's visits).

(2) M has some awareness of her environment (demonstrated by her awareness of discomfort, her responses in the snoozeroom, her responses during outings, and to music).

(3) She has some understanding of language (demonstrated again by her occasional response to command, and to other remarks by carers such as K's comment about how she had "burned my boobies" and Mr. Badwan's question: "are you a New York Girl?"

(4) She has on occasion spoken words herself (for example, "hello", "where am I?" "bloody hell", "morning").

(5) She opens her eyes and sometimes appears to watch people and her surroundings (for example, if people are talking, or in the snoozeroom).

(6) She moves her arms on occasions in a way that indicates her mood and needs.

(7) She makes noises - different sounds in different circumstances. The inference is that she uses her capacity to make noises as a means of communicating her needs.

(8) She responds differently to different people (for example S, Physio L and Mr. Badwan).

(9) She has responded on a number of occasions to music – both upbeat music and to love songs and ballads.

(10) When taken out in the Spring of 2011, she responded in a number of ways as described by Nurse O and Skills Worker H. There is some evidence that her overall responsiveness has increased since the outings took place.

(3) The evidence of Helen Gill-Thwaites: the SMART assessments

175. Helen Gill-Thwaites trained as an occupational therapist. For over twenty years, she has worked at the Royal Hospital for Neuro-disablity in London and has developed an internationally-recognised expertise in the assessment of brain injury. She has played a leading role in the development of the SMART.

176. In evidence, she pointed out that there are several unique features to SMART which enhance its sensitivity to the identification of awareness. One such feature is that the SMART protocol requires repeated assessment over time, thereby allowing the assessor to become familiar with the patient's behavioural repertoire, thus helping to discern any motor responses which may be utilised to elicit meaningful and reproducible behaviours. In addition, SMART provides an extensive range of assessment techniques across all of the sensory modalities (visual, auditory, tactile, olfactory and gustatory) plus motor function, functional communication and wakefulness/arousal, which provides the patient with the optimal opportunity to demonstrate their potential.

177. As summarised above, SMART consists of both formal and informal components. The formal component requires an assessment by the SMART assessor over ten sessions within a three week period. There are two aspects of the formal assessment component – the SMART Behavioural Observation Assessment and the SMART Sensory Assessment. The SMART Behavioural Observation Assessment comprises ten times ten minute formal observations of patients' behaviours at rest. At the end of the ten assessments, the behaviours are categorised as reflexive, spontaneous or purposeful, and the frequency of these behaviours is calculated. The SMART Sensory Assessment consists of twenty-nine sensory techniques which include, for example, in the visual modality, techniques such as visual tracking. A range of techniques is presented across all of the modalities to elicit behavioural response.

Each of the technique responses within each of the modalities (except wakefulness/arousal) is scored on a five-point hierarchical scale ranging from level 1 (no response), level 2 (reflex), level 3 (withdrawal), level 4 (localising) and level 5 (differentiating). The responses are further categorised by the frequency with which they are displayed. A "consistent response" is defined as one that occurs during at least five consecutive assessment sessions. A "frequent inconsistent response" does not meet the requirement for a consistent response, but occurs five times non-consecutively during the ten assessment sessions. A "highest inconsistent response" is the highest response observed in the modality that occurs on one to four occasions during the ten assessment sessions. Under the SMART protocol, a consistent meaningful response at SMART level 5 in any one of the sensory, motor or communication modalities is indicative of awareness.

178. The informal component of SMART is completed by carers, family and friends and consists of a "Communication Lifestyle History Questionnaire" (CLHQ) and a further assessment tool known as a "SMART Inform." The CLHQ provides the SMART assessor with an overview of the patient's interests, likes and dislikes. The information from the CLHQ is also used to further assess a known preference for different stimuli, such as music, taste, touch and smell. The SMART informs require carers and relatives to describe any responses observed during day to day activity seen during the time since the incident leading to the brain injury. This information enables the SMART assessor to categorise the response within the five SMART levels to allow comparison with the results gleaned from the SMART formal assessment. This information would also be used to customise the SMART treatment programme if a significant response has been observed by carers and relatives but not noted in the SMART formal assessment.

179. Miss Gill-Thwaites carried out SMART assessments with M in 2007 and 2011. In the first stage of the formal component of the 2007 SMART assessment – the behavioural observation assessment – M's behaviours were noted as being all either reflexive or spontaneous with no evidence of any purposeful behaviour. Furthermore, the behaviours were not significantly influenced by environmental stimuli. However, the sensory assessment produced more positive results. The assessment process was hampered by the difficulty in ensuring that M opened her eyes sufficiently frequently to undertake the assessment. Miss Gill-Thwaites reported that, once M's eye or eyes were opened and her attention gained, she was able to consistently focus and track an object and follow commands to move her left arm up and down. Thus, in the auditory modality, M was able to demonstrate a consistent response at SMART level 5 discriminating between the commands "move your arm up" and "move your arm down". Miss Gill-Thwaites reported that these responses were incompatible with a vegetative state. There was consistently no response in the olfactory modality, and only limited significant response in the gustatory modality. In the motor function modality, however, some of the responses observed were at SMART level 5. In the course of this part of the assessment, M was able to demonstrate a "frequent inconsistent" ability to press a switch to command and track a photograph of a baby, and a "highest inconsistent" ability to answer questions using the switch.

180. A video recording of part of this test was taken and supplied to the court in the course of the hearing. Of particular note were the ability to track a picture and the ability to raise and lower her arm on command. Most striking of all was her speedy response to

a command to press the switch, not once but twice. In oral evidence, Miss Gill-Thwaites explained that the significance of the response to command was that the patient has to go through a cognitive process of understanding what she was being asked to do (for example, the command to press the switch) and then having the ability to move in response and comply with the command (by pressing the switch). On the occasions when she pressed the switch twice, this would clearly involve a double response. Miss Gill-Thwaites described the behaviour exhibited by M of pressing the switch promptly twice in response to command as "a good result".

181. The information gleaned from the informal components of the SMART assessment within 2007 was less supportive of a diagnosis of consciousness. In other words, family and the carers then looking after her in hospital did not report responses at the same level as were observed during the formal component of the assessment. Nonetheless, Miss Gill-Thwaites concluded in 2007 that "based on the results of SMART, I would suggest a diagnosis of at least a minimally conscious state for M with a recommendation to explore her to further develop her response range and quality with a specifically designed SMART treatment programme". In order to optimise results, Miss Gill-Thwaites advised it was essential to provide appropriate positioning, preferably in a wheelchair with optimal head support, rather than allowing M to remain in bed. During the assessment, it was only when positioning was optimised that M had demonstrated behaviours indicative of a minimally conscious state.

182. Following the first SMART assessment, M was admitted to the Royal Hospital for Neuro-Disability on 12 September 2007 for further specialist assessment of her level of awareness. The hospital noted during the initial examination that it was

> "quite apparent that M was not in a vegetative state by demonstrating the ability to respond purposefully to a simple command. She displayed marked hyper-sensitivity, and squeezed her eyes tightly shut most of the time. When her eyelids were held open, the pupils were both equal and reactive to light, the gaze was not divergent, nor was there any mystagmus (insert definition) noted. In fact, there was evidence of eye tracking and fair fixation of gaze" (see report of Dr. T, physician at the profound brain injury unit at the hospital).

However, despite showing what are described as "islets of ability" to respond to basic commands, and hence selected awareness of certain aspects of her external environment, M was unable during the admission to demonstrate a consistency of high level responses that could be incorporated into function. As a result, the hospital concluded that no further therapeutic intervention was advisable or appropriate at that stage. In describing the results from the 2007/8 hospital admission, Miss Gill-Thwaites observed in evidence that the staff had tried many avenues but were unable to move M on to being able to establish a consistent yes/no response. Although M was observed to follow commands, as had been seen during the SMART assessment, the hospital staff were unable to help her move on to the next stage, which would be linking that capacity to a yes/no response so that she would have been able to begin the process of communication.

183. For the second assessment, Miss Gill-Thwaites met M at her care home in May 2011 and all of the assessments conducted on this occasion took place in M's bedroom. On

this occasion, the first stage of the formal component of the SMART assessment – the behavioural observation assessment – produced similar results to that obtained in 2007. In other words, M's behaviours were again either reflexive or spontaneous, with no evidence of any purposeful behaviour. Once again, her behaviours were not significantly influenced by environmental stimuli. Her behaviours were broadly the same as those exhibited in 2007. As in the previous test, however, the other component of the formal assessment – the sensory assessment – produced more positive, albeit complex, results. The assessment of the visual modality responses was again complicated by the difficulty in ensuring that M kept her eyes open. Focusing and tracking were less consistent than in 2007 although still evident. Furthermore, although discrimination had been evident in 2007, no such ability was detected in 2011. Some responses to auditory stimuli, however, were demonstrated at SMART level 5 in 2011, albeit not as consistently as in 2007. As in 2007, the majority of her responses in the tactile modality were reflexive, that is to say, compatible with the vegetative state and there was no evidence of any head turning towards stimuli in 2011. As 2007, there were no significant responses in the olfactory modality, and limited significant responses in the gustatory modality. Whereas, in 2007, she demonstrated the consistent ability to perform a verbal instruction, and an infrequent but inconsistent response to the use of a switch, only very limited responses of this type were seen in 2011.

184. The overall conclusion of the sensory assessment element of the formal component of the 2011 assessment was that there was less evidence of an ability to visually discriminate and track, partly due to difficulty in getting M to open her eyes during assessments, but that she "still demonstrates rare but significant interactions with the environment and stimuli". Responses seen on this occasion included a nod to a question, mouthing words, and an attempt to write. In oral evidence, Miss Gill-Thwaites described how, during the 2011 assessment, when she was shown a card and asked "Is this coffee?" M had mouthed a word in a way which Miss Gill-Thwaites, with her experience of SMART assessments, concluded was an attempt to read the words. In the same session, when Miss Gill-Thwaites said "hello", M responded with a short sound which Miss Gill-Thwaites regarded as a response to what she had said.

185. As in 2007, it was not possible for Miss Gill-Thwaites to complete the communication lifestyle history questionnaire, the first element of the informal component in the SMART assessment, but she was able to obtain the so-called SMART informs with the assistance of observations from members of M's family and staff at the care home. On this occasion, the information from care staff was more indicative of consciousness than the observations of the hospital staff in 2007. Thus the findings from the formal and informal components of the 2011 SMART were consistent. In both formal and informal assessment and observation, meaningful responses were noted, albeit infrequently.

186. Following completion of the assessment, Miss Gill-Thwaites accompanied M to the snoozeroom at the care home. In oral evidence, Miss Gill-Thwaites said that during the period of observation in the snoozeroom, M had opened her eyes throughout the session. She had looked towards the right at the lights on the wall. From this observation, bearing in mind the great difficulty that has been experienced in trying to get M to open her eyes during the assessment, Miss Gill-Thwaites concluded that the greater stimulation present in the snoozeroom was a pointer to how best to proceed

with seeking to improve M's responsiveness. "The more stimulating the environment, the more likely we are to see a response than being in a room and quieter. It is worth exploring."

187. Miss Gill-Thwaites' conclusion from the 2011 SMART assessment was that M was still demonstrating behaviour suggestive of minimally conscious state. Whilst the meaningful responses were largely less consistent during the formal assessment, the observations by the team of carers were slightly more frequent than in the equivalent stage in 2007. However, Miss Gill-Thwaites added that the meaningful responses were infrequent, and there is no pattern as to when they might occur. In reply to a question from Mr Sachdeva, Miss Gill-Thwaites conceded that the reduction in the discriminatory behaviours particular in the visual and auditory modalities between the 2007 and 2011 assessments was significant. She did not however necessarily consider that this indicated a reduction in functionality. This was something that might be explored in a further treatment programme. There is less tracking and localising towards stimuli, but in Miss Gill-Thwaites opinion this is partly due to the difficulty in gaining eye opening. Unfortunately, however, M still has no ability to communicate in a functional way, although she does on occasions, answer questions with a spontaneous retort. Miss Gill-Thwaites' overall opinion, however, is that, notwithstanding the disappointing outcome from the admission to Putney following the 2007 SMART and the absence of any subsequent improvement, M has maintained approximately the same status since the earlier assessment in 2007 and there are grounds for further exploration. She observed: "I am seeing potential there, there is definitely potential and there are these little islands of very significant responses. But the question is can we make that more consistent to make it functional?" Her proposal is that a more stimulating setting and activity programme may lead M to open her eyes more frequently and as a result increase her responsiveness.

188. In cross-examination Miss Gill-Thwaites said that she was unable to see any adverse effects of a more stimulating environment, providing she was being looked after safely. She did not observe any distress or any adverse response or "hypersensitivity" in the snoozeroom. She agreed that it was possible that what was described by some as "hypersensitivity" is attributable in part, at least, to the fact that she has not had the opportunity to experience sensations and that, if she had that opportunity, the hypersensitivity might abate. She also thought that it would be beneficial to M to have photographs and possessions around her. She saw no disadvantages in having photographs in her room. Miss Gill-Thwaites thought that M would only benefit from a more stimulating environment and said that it would be of interest to see how she would respond in those situations. The purpose of introducing greater stimulation would therefore be both to enrich her life and to see whether she demonstrated an increased response.

(4) The medical expert evidence

189. Expert evidence at the hearing was given by Mr. Derar Badwan and Professor Turner-Stokes.

190. Mr Badwan is the lead clinician in rehabilitation medicine at the University Hospital of Coventry and Warwickshire. His interests are in the field of neurological rehabilitation spanning brain injury, stroke and multiple sclerosis. He has a special interest in the assessment and management of people with severe brain injury,

particularly those in the vegetative or minimally conscious states and associated problems. Over the past sixteen years, he has developed extensive experience in the assessment and treatment of persons in those states and has established a service for them at the Royal Leamington Spa Rehabilitation Hospital, which is one of two establishments in the country (the other being the unit at Putney) that provide a specialist input for such patients who are admitted from primary care trusts across the country.

191. Professor Lynne Turner-Stokes is a Consultant Physician in Rehabilitative Medicine, Director of the North-West Thames Regional Rehabilitation Unit at Northwick Park Hospital and Herbert Dunhill Professor of Rehabilitation at King's College Hospital, London. Her curriculum vitae demonstrates that she has an exceptionally high level of expertise in the field of rehabilitation medicine. Her clinical responsibilities include her principal area of practice in complex neurological disability in younger adults, but also a wide range of rehabilitation services for a catchment area exceeding 5 million people, which inter alia provides neuro-palliative rehabilitation including disability management for persons in low awareness and vegetative states. She is responsible for a number of important research projects, including the development of a common language in disability measurement, the assessment of needs for nursing care and rehabilitation needs, the evaluation of specific interventions, the assessment of tools to measure function, the evidence for effectiveness of rehabilitation, and user and carer experience in complex disability. She is the author of in excess of one hundred published articles and has a wide range of other professional responsibilities. Amongst those, she is currently chairing a working party updating the RCP document "The vegetative state" last published in 2003. She has been involved in medico-legal work for over 18 years.

192. As described above, Mr. Badwan's first report in April 2007 had a profound influence on this case. Prior to that point, it was the consensus amongst clinicians, including Professor Andrews, that M was in a VS. It was Mr. Badwan who first suggested that her level of consciousness might be higher, and subsequent tests have proved that he was right. The first report from Professor Turner-Stokes was filed on 12th July 2009, followed by several supplementary letters. This was followed by another report from Mr. Badwan on 28th July 2010. Prior to the hearing before me, the experts met and prepared a joint report highlighting areas of agreement and disagreement. Subsequently, Mr. Badwan prepared two addendum reports on 10th July 2011, and Professor Turner-Stokes responded with a longer supplementary report dated 19th July 2011. Both attended to give oral evidence and each was able to hear the other's evidence.

193. In their joint report, the experts agreed (1) that M remains in a MCS as opposed to a VS; (2) that the second SMART assessment neither demonstrated evidence of increased awareness/interaction with her environment, nor provided evidence of deterioration in her level of awareness, and (3) that it was not possible to determine the extent of M's level of awareness of herself, others, her environment or external stimuli, although her responses suggested that she had some awareness of herself, and her environment, and has both positive and negative responses to stimuli. They disagree, however, about a number of important issues, notably as to (1) where M's level of consciousness lies on what Professor Turner-Stokes described as the "broad spectrum of consciousness" covered by MCS; (2) whether it is in her interests to be

exposed to further stimuli, and (3) whether her experiences are on balance positive or negative. They also disagree on the ultimate question – whether it is in M's best interests for ANH to be withdrawn.

194. In his reports, Mr Badwan consistently expressed the view that M is at a higher level of awareness. In his second report dated 28 July 2010, he pointed out that M had demonstrated several behaviours that are consistent with the diagnosis of minimally conscious state and that she had shown more complex behaviour than a single behaviour of low complexity. He therefore concluded that M was not near the border between MCS and VS but rather at a higher level and said that he was "certain that such diagnosis continues to be applicable." I felt, however, that the clarity of this opinion was somewhat obscured in his oral evidence during which he said that he did not think it was helpful to talk of levels of MCS.

195. Mr. Badwan made further recommendations as to how her abilities might be maximised for example by attending to her posture, proposing continued direct interaction with members of staff through talking, music, watching television, going through family photographs etc. Given the difficulties that M experienced in keeping her eyes open, he suggested that these activities might be augmented by using listening books. All of these activities should be interspersed with periods of rest. He advised that she should be taken outside the nursing home for the purpose of examining and establishing her response to an outside environment. Given the concerns expressed by Professor Turner-Stokes about hypersensitivity (see below), Mr Badwan suggested that these visits should be managed carefully. Despite his view that M was at a higher level of awareness than that diagnosed by Professor Turner-Stokes, Mr Badwan agreed with the professor that further improvement was unlikely, although he noted that there were occasional reports in the literature of such recovery occurring.

196. Mr Badwan did not agree that there was no aspect of her life which gave her pleasure. He noted that she resides in a comfortable environment. He rightly described her care regime as excellent. He said that he was "certain that M is not experiencing constant pain or discomfort". Furthermore, he identified some evidence that she continues to find some enjoyment at times at certain activities. So far as her distress whilst listening to music was concerned, he observed: "if one is to accept that at times she becomes upset when listening to certain songs, then one has to accept the opposite, i.e. that she can experience pleasure at other times". Mr Badwan further considered that on at least two of the four outings, M's experience was positive and possibly on a third outing. In all circumstances, he believes that it is possible that M would respond to stimuli that would enhance the quality of her life. He believes that M is able to appreciate and interact with her environment, for example her vocalisation when requiring attention to her hygiene, which could be interpreted as a basic level of communicating need.

197. Mr Badwan prepared two further short reports following a final visit to M on 9 July 2011 shortly before the start of the hearing. After observing her displaying various responses, he concluded that M's medical condition remained stable. He observed that she was well cared for and described her care provision as excellent. He noted that she had again exhibited behaviour on this visit that indicated that she was aware of herself and her environment. He confirmed that she is able to respond at times appropriately to verbal commands, although this remains inconsistent. He confirmed

that M remained in a MCS and he did not consider her condition had deteriorated to any extent since her assessment at Putney in 2007. He confirmed his view that there was no evidence of hypersensitivity to light or any other stimuli. He demonstrated this by pointing out that her exaggerated responses to such stimuli were markedly reduced when actions that were to be undertaken were explained to her beforehand. In Mr. Badwan's oral evidence, he referred to how M had jumped when he clapped his hands without warning but not when he warned her in advance that he was going to clap. Cross-examined by Mr Sachdeva, he said he thought there were signs in M of interaction and recognition of objects that are worth exploring.

198. Later in cross-examination by Mr. Sachdeva, Mr Badwan expressed the view that ANH should never be withdrawn from a patient in a MCS, although in re-examination he conceded that if such a patient was in the terminal stages of a disease such as cancer different circumstances would apply.

199. In her first report, Professor Turner-Stokes summarised her conclusions as follows:

> "M has sustained profound brain damage as a result of brain stem encephalitis in 2003. She is in a minimally conscious state, but at the lowest level, effectively on the border of a vegetative state. Although she has certain responses that indicate a very limited level of awareness of her environment, none of these can be harnessed to allow meaningful interaction, communication or the ability to make choices at any level. I am unable to identify any aspect of her life that gives her positive pleasure or satisfaction. On the contrary she has marked hypersensitivity and it is evident that she experiences a significant level of discomfort and at times pain. Her condition has not changed significantly in the last five years and there is no realistic possibility of recovery. She lacks mental capacity to make decisions regarding her care and treatment, and so any such decisions must be made on the basis of her best interests. Her family is united in their view that she would not want to be alive in her current condition. In my opinion it would be appropriate to withdraw artificial nutrition and hydration and allow her to die in dignity. If this is not done, she may live for another ten to twelve years with considerable burden and distress to herself and to her family."

200. In a letter which accompanied her report, Professor Turner-Stokes confirmed that she was of the view that ANH would be appropriately withdrawn, adding: "even though I recognise that this is probably a departure from the law as it currently stands (or at least as I understand it)."

201. Professor Turner-Stokes prepared a supplementary medical report dated 19 July 2011. The purpose of this report was to comment further on the second SMART test carried out in May-June 2011 and also on the results of a further WHIM test carried out in early July 2011. She carried out an analysis of the activity/response records made on M's outings in the spring and early summer 2011. She observed that M appeared to be sensitive to the wind and to light. She noted a number of possibly positive responses, including (a) opening her left eye and appearing to be looking around; (b) appearing to relax when sitting quietly in the sun, and (c) appearing to turn her head into the sun. She noted a number of possibly negative responses, including (a) grimacing in response to the breeze; (b) holding her eyes tightly shut; (c) a hunched or

tensed posture whilst being pushed in the chair and (d) closing her eyes when visual contact was made. She also noted some possible localising responses of behaviours, including (a) appearing to turn her head into the sun; (b) appearing to turn her head to the right as if sheltering from the wind and (c) appearing to be looking round. Professor Turner-Stokes notes that no discriminating interactions with the environment were observed. She concluded "there is no clear evidence that these outings endanger discomfort or distress. Equally there is no positive evidence that they afford pleasure or add to M's quality of life."

202. Professor Turner-Stokes noted that other activity/response records report occasional high level or discriminating responses including (a) possible specific responses to certain songs; (b) isolated production of single words or short phrases either in response to questions or spontaneously and (c) on one occasion appearing relaxed while having her right foot massaged but responding negatively to having a left foot messaged.

203. Professor Turner-Stokes prepared a most useful table summarising the WHIM score from the various witness statements and activity response records prepared by members of the care staff, plus the scores arising out of other professional assessments. She concluded that the ratings gave a reasonably consistent picture. Of the sixty-two items on the WHIM scale, the first fourteen are compatible with vegetative state. M, however, was noted to exhibit a number of types of behaviour above those fourteen. Items fifteen to eighteen were reported by carers and at least one other professional at a level which Professor Turner-Stokes characterised as reproducible. Items twenty to twenty three on the WHIM scale were reported by carers only at a level categorised as reproducible. Some other isolated behaviours at a higher level were reported at a level which Professor Turner-Stokes described as sporadic. She concluded that, whereas items up to fourteen were compatible with a vegetative state, "items fifteen to eighteen clearly place her in a state of MCS as opposed to VS". Professor Turner-Stokes observes that this "concurs with the conclusions from the repeat SMART tests". In short, "M shows inconsistent, but clearly reproducible, responses above a level compatible with VS and is therefore in MCS. The WHIM scores by professionals have been helping in corroborating the behaviours reported by carers. However, her range of reproducible behaviours falls in the lower third of the WHIM scale and her level of awareness interaction is substantially lower than that demonstrated by many of the patients in our series" who were progressing towards emergence from MCS. As there was no indication of improvement between 2007 and 2011, she thought it "highly improbable" that M would emerge from MCS. She placed this probability at less than five per cent although she stresses that this is "only an intuitive estimate in the absence of formal data". She does not consider it likely that a further stimulation programme at this stage will significantly alter the likelihood or emergence from MCS. In oral evidence, she confirmed that it was improbable that M would ever emerge out of a MCS, given the severity of diffuse brain injury suffered, the fact that she has been in this condition for over eight years, and the absence of evidence of any upward trajectory in her level of consciousness and behaviour, together with some suggestion in the 2011 SMART assessment of a reduction in her discriminating activity.

204. In cross-examination by Miss Harry Thomas, Professor Turner-Stokes was asked about evidence from the 2011 SMART assessment that M had been seen mouthing

words. She thought it might be worth exploring but did not think it amounted to evidence that she will emerge from MCS. Later she was taken to four occasions since April 2011 when M had apparently vocalised words. Asked if that could equate to a high level of awareness around that time, Professor Turner-Stokes said “yes and no”. She accepted that three of the occasions of apparent vocalisation were responses to others. She thought it was “quite hard to know what is meant by those”. Miss Harry Thomas suggested that this greater level of vocalisation might be attributable to the greater stimulation she had experienced since being taken on outings. Professor Turner-Stokes accepted this as one explanation, amongst others, such as the possibility of over-interpretation, and the fact that M was under a greater degree of observation in preparation for this hearing.

205. In three respects, Professor Turner-Stokes modified her views during the course of her involvement with this case. The first concerns the relevance of certain factors to the issue of withdrawal of ANH. In her first report, in addition to the burdens which M herself would suffer if ANH was continued, Professor Turner-Stokes took into account two other factors:

> “The considerable distress of her family at seeing her in this state of discomfort will also be prolonged. In addition, whilst it should not weigh substantially in the argument of in comparison with M’s best interest, there are considerable costs to the State of maintaining her in the best possible condition minimise to distress and discomfort. Given that resources are limited, this inevitably means that expenditure in this quarter (which could amount to £1m or more over the remainder of her life) results in deprivation of healthcare funds available for other patients, in whom they could potentially make a real and substantial to quality of life.”

206. In her supplementary report, however, Professor Turner-Stokes significantly modified this part of her opinion. She acknowledged that the legal question to be determined by the court is that of M’s best interests only. She therefore recognised that any external factors are not relevant to the case and added:

> “I therefore formally resile from the broader assessment of impacts contained in my earlier report – specifically, neither the benefits to the carers nor the burdens to the family and to the State are relevant to the case currently before the court”.

207. The second aspect on which she changed her opinion was the reliability of observations made by care staff. In her first report, she expressed the view that the accuracy of some of the reports “appears to be questionable”. Professor Turner-Stokes observed that it was evident that M’s carers were highly committed and caring. Given any level of uncertainty, it was entirely appropriate, according to Professor Turner-Stokes, that they were sensitive to any signs that there might possibly indicate attempts on M’s part to communicate. She warned however that this led to a risk of over-interpretation. There was, she said, “a tendency to report more and more incidences of interaction which may artificially heighten their collective beliefs about her level of response”.

208. In her second report, Professor Turner-Stokes was less concerned about the accuracy of the care staff observations of M’s behaviour. She said that she had no reason to

doubt the factual information contained in the reports and observed that, between them, they provide useful confirmation of some inconsistent, but discriminating behaviours. She maintained, however, that some of the staff comments were interpretative and thus merely conjectural. In fairness, Professor Turner-Stokes also pointed out that it is very difficult to determine whether a patient in VS or MCS is registering what they are seeing when they apparently gaze at something or someone for quite a long period of time. She observed that, if she finds it challenging even after more than twenty years of working with patients in low awareness states, it is not surprising that carers and professionals with much less experience find it difficult to interpret what they are seeing.

209. In oral evidence, Professor Turner-Stokes said that, when she had first seen the papers, she had been concerned that some of the observations noted by care staff at the nursing home of types of behaviour above the VS level in the WHIM scales were examples of over-interpretation. Now that a more systematic analysis has been carried out, including observations by other professionals that corroborate the presence of types of behaviour above the VS level, Professor Turner-Stokes is more confident that the carers' observations are accurate.

210. I find that the formal assessment using the SMART and WHIM tools has indeed largely corroborated the observations of the care staff. This gives me additional confidence in the reliability of their evidence. In addition, Professor Turner-Stokes fairly acknowledged that carers do become familiar with interpreting a patient's behaviour over time. Common sense suggests that, as a general rule, the greater the experience a carer has of working with a patient in an MCS, the more familiar he or she will be with the nuances of the patient's behaviour. Carers with extended and recent experience of the patient will thus be better equipped at interpreting that behaviour. In this case, in contrast with the family members, nearly all of the care staff at the nursing home who were called to give evidence have had extensive and recent experience of M's behaviour. Accordingly, and having heard them in the witness box, I find that I can give considerable weight to their evidence as to M's behaviour, fortified by the fact that these interpretations have been substantially corroborated by the formal assessments carried out using the SMART and WHIM processes.

211. The third matter on which Professor Turner-Stokes's views have changed is M's level of awareness. On the occasion of her first visit, in 2009, Professor Turner-Stokes carried out a WHIM test which suggested that she was at the lower end of the MCS spectrum. In her first report, this led her to warn that, for a patient who was on the borderline between MCS and VS "a higher level of awareness is not necessarily a good thing. The physical sequelae of severe brain injury can be painful and distressing, so that a level of awareness of self or the environment can engender symptoms".

212. In her supplementary report dated 19th July 2011, after the second SMART assessment and with the benefit of her own comprehensive analysis of the WHIM scores, Professor Turner-Stokes modified her view as to where M lies on the MCS spectrum. As M's responses "fall considerably short of functional interactive communication" she does not agree with Mr Badwan that M is at the upper limit of MCS. However, in contrast to her position in the previous report, Professor Turner-Stokes now accepts, in the light of the care staff witness statements, the

activity/response sheets, and her own recent observations, coupled with those made by Miss Gill-Thwaites and Mr. Badwan, that M's level of behaviours and responses places her at a moderate level of MCS.

213. In her oral evidence, Professor Turner-Stokes was asked a number of questions about aspects mentioned in her reports, namely pain and hypersensitivity. Professor Turner-Stokes said in oral evidence that it is extremely difficult to evaluate a patient's level and experience of pain when they are unable to communicate. One can only go by responses. There are a variety of tools used, such as the Abbey scale developed for dementia patients, but Professor Turner-Stokes advised that all or nearly all of these still require validation for use in MCS cases. Research evidence suggests that patients in MCS may be able to experience pain in similar ways to "normal" individuals. Whereas patients in VS may react reflexively and thus appear to respond, but are in fact lacking the part of the brain that appreciates and experiences pain, evidence suggests that in MCS patients these pathways are relatively intact. Cross-examined by Miss Harry Thomas on this point, Professor Turner-Stokes gave a more technical explanation. The interconnective link required to experience pain is between the somatosensory cortex (the part of the brain that received messages of pain through the brain senses) and the fronto-parietal cortices (the part of the brain where one experiences and associates pain). Recent research (Boly et al "Perception of pain in the minimally conscious state with PET activation: an observational study", The Lancet (2008) 7: 1013-1020) has postulated that this link is present in MCS but not in VS.

214. Professor Turner-Stokes was asked a number of questions about her opinion that M suffers from hypersensitivity and that as a result it may be contrary to her interests to expose her to additional stimuli. Cross-examined by Miss Harry Thomas, she accepted that the symptoms which she interpreted as indicating hypersensitivity could be seen as an indication of awareness and interaction between herself and her environment, but said that M's apparent withdrawal on experiencing stimulation (such as scrunching up her eyes in bright light) was evidence that she was experiencing it as an allodynia (that is to say, an unpleasant sensation). Treatment of hypersensitivity in MCS cases was difficult because cognitively behavioural approaches were not suitable. One option would be to increase stimulation in the hope that it reduced her sensitivity, but this was not always successful and while being carried out would be likely to cause further distress.

215. On the ultimate question in this case, Professor Turner-Stokes accepted in her supplementary report that, when considering the question of withdrawal of ANH, the issues are more complex for persons in the MCS than for those in VS, for a number of reasons. First, the diagnostic criteria for VS are more easily defined. By contrast, MCS covers a broad range of awareness and responsiveness "so inevitably there will be a range of clinical opinion with respect to the individual's level of awareness". Secondly, whereas there are established criteria for a permanent vegetative state from which meaningful recovery is considered to be at least highly improbable, there are, as yet, no established criteria for a "permanent MCS" and data are currently lacking in the world literature to determine the point beyond which meaningful recovery is highly probable. Thirdly, persons in VS are considered to have no awareness of self or their environment, and so are not likely to experience pain or discomfort in the process of dying. Persons in MCS, on the other hand, most probably have near

normal perception of pain and discomfort and so are likely to experience symptoms of starvation and dehydration after ANH is withdrawn."

216. In continuing to support the withdrawal of ANH, however, Professor Turner-Stokes in her supplementary report summarised the arguments as follows. First, M has a very profound physical and cognitive impairments and is in a MCS. Secondly, although she makes certain limited responses that indicate awareness of her environment, she is unable to communicate effectively or make basic choices even at the lowest level. She has no functional communication. Thirdly, Professor Turner-Stokes observes that M's balance of experience in her current condition "remains a matter for continued concern". She highlights the fact in particular that M is bed or chair bound, doubly incontinent and totally dependant on nursing care.

217. In expressing her overall opinion in oral evidence, Professor Turner-Stokes said that, whilst recognising it was a matter for the court, she would support the withdrawal of ANH, given that it is very improbable that M will ever emerge from the MCS and that, in Professor Turner-Stokes's view, her negative experiences outweighed her positive ones. She noted in her oral evidence that no-one had been able to 'positively identify things that cause specific pleasure' and that the 'positive' experiences had to be viewed in conjunction with the negative aspects of M's experiences. She acknowledged that, when ANH was withdrawn, M would have negative experiences while she was dying, but these could be ameliorated by medication and other treatment and, in Professor Turner-Stokes's view, it would be in M's best interests to endure this short-term negative experience rather than the prolonged negative experience of living, possibly for several further years, in a MCS. She summarised her opinion in these words: "as a general principle, if a person would not have wanted ANH to keep her alive, I would personally support its withdrawal from that person in order to allow them to die with dignity rather than allow them to continue that negative experience over many years …. In the absence of evidence that M is going to emerge from MCS I would apply my general principle". For Professor Turner-Stokes, the three important factors are (1) what M wanted or would have wanted (2) the high probability that she will not emerge from MCS and (3) the overall negative balance of her future experience, taking into account when striking that balance the fact that, unlike a patient in VS, someone in MCS would experience short-term suffering, albeit mitigated by careful treatment, during the withdrawal of ANH.

218. Professor Turner-Stokes accepted that, if ANH were not withdrawn, it must be in M's best interests to take steps to try to improve her quality of life, and in those circumstances it might be appropriate to try exposing her to increased stimulation. She was clear, however, that in those circumstances decisions about the prescription of antibiotics was a matter to be left to the clinicians.

BEST INTERESTS ANALYSIS

219. In analysing whether it is in M's best interests within the meaning of section 4 of MCA for ANH to be withdrawn, there are a number of important factors which require careful scrutiny.

Preservation of life

220. The first principle is the right to life. As Lord Goff observed nearly twenty years ago in the Bland case, "the fundamental principle is the principle of the sanctity of human life". Munby J in the Burke case (*supra*) spoke of the "very strong presumption in favour of taking all steps which will prolong life". Paragraph 5.31 of the Mental Capacity Act 2005 Code of Practice requires that "all reasonable steps which are in the person's best interests should be taken to prolong their life". As Miss Harry Thomas stated in her final submissions, "the starting point in this application and all applications involving the withdrawal and withholding of life sustaining treatment is the presumption in favour of the preservation of life". It is not an absolute right. As Lord Goff said in *Bland* "there is no absolute right that a patient's life must be prolonged by treatment or care, regardless of the circumstances." Nonetheless, it is a fundamental right, as all subsequent cases have recognised, both in this jurisdiction, in the European Court of Human Rights, and across the world.

221. Furthermore, unlike Tony Bland, and other patients in the VS, M is conscious, albeit minimally so. She is sensate, clinically stable, aware of herself and her environment, able to respond to people, and to music, and also, in a very limited way, to communicate about her needs. In short, she is recognisably alive in a way that a patient in VS is not.

222. The principle of the right to life is simply stated but of the most profound importance. It needs no further elucidation. It carries very great weight in any balancing exercise.

M's wishes and feelings

223. The second factor requires more extensive analysis. As set out above, s.4(6) of the MCA requires the court to consider, so far as reasonably ascertainable, M's past and present wishes and feelings. Even though M made no formal advance decision as to medical treatment, it is said on behalf of the Applicant that she expressed wishes and feelings about the matter which should be give significant weight when deciding whether ANH should now be withdrawn. Indeed, Mr Sachdeva and Miss Butler-Cole on behalf of the Applicant say that this factor should be given decisive weight and place M's wishes and feelings at the forefront of their argument. M's family feel strongly that she would have rejected her current treatment and the rationale for this application is fundamentally based on M's perceived wishes and feelings. They submit that those who oppose this application fail to give appropriate respect to M's wishes and feelings about the right to choose her life and the manner of her death.

224. The Applicant's counsel draw my attention to the summary of post-MCA case law on the importance of wishes and feelings in the judgment of Morgan J in *Re G (TJ)* [2010] EWHC 3005 (COP). They stress various statements in the Code of Practice, in particular para 5.32:

> "All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment."

I have that passage firmly in mind, along with para 5.38:

> "In setting out the requirements for working out a person's 'best interests', section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now."

Of course, the Code goes on to add:

> "But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests. Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests."

Nevertheless, the Code clearly envisages that wishes and feelings will be a very important part of the best interests analysis, as confirmed by para 5.41:

> "The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)."

225. Mr. Sachdeva and Miss Butler-Cole acknowledge the difficulty facing the Court in deciding what weight to attach to M's previously expressed wishes, in view of the fact that she was never required to think specifically about being in a minimally conscious state and that there is neither an advance decision nor any written statement. They rely, however, on the evidence given by B and S as to M's views about dependency and dignity at the end of life. They submit that these views are relevant, as they indicate what her starting point was likely to be, and the factors on which she would have placed weight. They remind me in particular of the unchallenged evidence that M felt that someone in the condition of Anthony Bland ought to be allowed to die. It is submitted on behalf of the Applicant that it can be safely assumed that M would have been, as her partner stated, 'horrified' by the thought of living in her present condition. In reaching a view about her situation, she would, they submit, have taken into account the extent to which she had conscious awareness of the world, the extent to which she was able to participate in and have conscious awareness of activities that had given her pleasure, whether she was experiencing pain, the quality of her daily life, the importance of not being dependent on other people, the fact that there was no realistic prospect of recovery, the distress caused to her relatives and partner as a result of her condition, and the importance of her wishes and feelings being respected by others. The Applicant's counsel acknowledge that the court will inevitably be concerned that, without knowing exactly what M would have thought of her actual condition, it is impossible to say she would have been certain about preferring death to continued existence in MCS. They submit, however, that according true respect to M's autonomy requires the court to consider seriously what M's view would have been, even if it cannot be conclusively determined, and to give it substantial weight. They accept that the more specific the statement, the more likely it is to be persuasive, but submit that it does not follow that more general statements should be ignored. In addition, they argue that the possibility that M (as she currently is) may hold different

views, having now experienced life in MCS, is not fatal to giving substantial weight to M's previous or likely views. They further contend that the possibility that M's present wishes are different from her likely wishes at a time when she had capacity should not hold as much weight as it might do if M were significantly less disabled. In M's case, her world has shrunk so much; her interests (from her perspective) are now so marginal; and her present self is so fundamentally incapable of sustained or consistent autonomous thought and direction even on the most basic level, that it is reasonable, submits Mr Sachdeva, to consider that her earlier expressed views and interests should take precedence.

226. On the question of M's wishes and feelings, the Official Solicitor submits that the law concerning advance decisions as developed by the courts prior to the MCA and then refined in ss 24 to 26 of that Act, whilst respecting the importance of personal autonomy, establishes a number of stringent safeguards and requirements. Miss Harry Thomas and Miss Apps submit that there are good reasons why the law, both at common law and under statute, insists on such stringent requirements before an advance decision can become binding, and in the absence of a valid binding advance decision that meets these requirements, the weight to be attached to any statements made by the patient must be limited. In this context, the Official Solicitor invites comparison with the American case of *Re Martin* 538 NW 2d 399 (1995 Mich Sup Ct) in which the Michigan Supreme Court stated that "clear and convincing evidence" of a patient's wishes was required to justify withholding treatment from patients in a MCS. "Only when the patient's prior statements clearly illustrate a serious, well thought out, consistent decision to refuse treatment under these exact circumstances or circumstances highly similar to the current situation should treatment be refused." Miss Harry Thomas drew my attention to similar observations in another American case, *Re Wendland* 28 P 3d 151 (2001 Cal Sup Ct). The Official Solicitor acknowledges that Article 8 requires that there must be respect for personal choice, self determination and personal autonomy where it is capable of being expressed, even where, to give effect to those express wishes, would result in the death of that person. He submits, however, that in a case such as this, concerning a person who cannot express her current wishes, where the consequences of a withdrawal of treatment will be the patient's death, previous statements of a general nature relating to the enjoyment of life, or dislike of nursing homes, cannot be decisive in determining whether that person, if capable, would now choose to die. Accordingly, whilst accepting that the statements made by M in the past as relayed by B and S are not irrelevant to the court's analysis of best interests, he submits they cannot carry decisive weight.

227. Miss Dolan on behalf of the PCT submits that the court should give due weight to M's previously expressed wish not to live a life dependent on others but recognising that these statements were not made in the context of the consequences of withdrawing ANH when conscious. She submits that there is no indication that M's statements on which the Applicant relies were made in contemplation of living in the specific circumstances in which she now lives. Miss Dolan points out that the advance decision provisions require the patient to have gone through a specific thought process of identifying the specific circumstances in which the advance decision will apply, knowing that the decision will indeed be decisive, in cases such as this, this involves understanding that the effect of the decision would be the withdrawal of ANH when in a MCS. Miss Dolan submits that, if the person has not addressed the question of

what those circumstances would be, and considered specifically the treatment that would be withdrawn, and the consequences of that withdrawal, the weight to be given to the statements should be limited, even when, as here, the statements are repeated on a number of occasions to more than one person. Miss Dolan also relies on the fact that many people are comfortable and content in a life of extreme disability, and not so affected by their disability as to want to terminate their lives.

228. It is unclear whether M ever had a detailed understanding of Tony Bland’s condition, but it does not follow from the fact that she indicated that she would not wish to be continue living in a VS that she would have wished to have ANH withdrawn when she was conscious, albeit minimally. In addition, I have to take into account the fact that M has lived in her current MCS for many years. We have no way of knowing how she now feels about her current life. In those circumstances, the court must be particularly cautious about attaching significant weight to statements she made before her collapse.

229. Mr. Sachdeva submits that if the possibility that an incapacitated adult had changed her mind after becoming incapacitated was “fatal to giving substantial weight to M’s previous or likely views …. then no advance decision could ever be upheld, on the basis that P could have changed his or her mind.” But the crucial distinction between an advance decision that meets the criteria required by ss 24 to 26 of the MCA and other expressions of wishes and feelings is that an advance decision must address specifically the circumstances in which it will be binding and is made in the knowledge that it will be decisive if those circumstances arise. In other words, an adult who makes an advance decision knows that it will be decisive in the event that he or she becomes incapacitated and is unable to communicate their current wishes and feelings.

230. I accept without qualification that B and S are accurately relaying the various statements made by M in the past. I accept, therefore, that when her grandmother and father were in declining health and moved to live in nursing homes, M said on more than one occasion words to the effect that she would not wish to live like that, that she would not wish to be dependent on others, and that she “wanted to go quickly”. I also accept the evidence that, when reports about Tony Bland appeared on television, M expressed views to the effect that it would be better to allow him to die. But, as conceded on behalf of the Applicant, there is no evidence that M ever specifically considered the question of withdrawal of ANH, or ever considered the question whether she would wish such treatment to be withdrawn if in a minimally conscious state. Furthermore, even if M did specifically consider those questions, there is no way of knowing her current views, having lived in that state for over eight years. Given the importance of the sanctity of life, and the fatal consequences of withdrawing treatment, and the absence of an advance decision that complied with the requirements previously specified by the common law and now under statute, it would be in my judgment be wrong to attach significant weight to those statements made prior to her collapse.

Pain

231. Mr Sachdeva invites the court to accept the evidence of Professor Turner-Stokes, supported by members of the family and carers, that M does experience pain and/or distress and/or discomfort on a regular basis. He reminds me that she has severe

spastic tetraparesis with joint deformity. She experiences distress and discomfort because of her incontinence. She needs regular repositioning. An Abbey Pain Scale test carried out by Professor Turner-Stokes confirmed that she was suffering pain, but the frequency of pain and/or discomfort is unclear. Her carers report that it occurs about twenty-five to thirty per cent of the time. Members of the family contend that it is a more frequent occurrence. Mr Sachdeva submits that a substantial proportion of her conscious experiences include the experience of pain, distress or discomfort. Furthermore, he says that it must follow that she will be at a real and significant risk of experiencing further pain and/or discomfort and/or distress if her condition were to deteriorate. Although such risks could be ameliorated by provision of pain relief, as she cannot reliably explain when she is in pain, there will always be a risk that pain relief or palliative care will not entirely remove the pain, discomfort or distress.

232. I accept that M, as a person in a MCS, can feel pain. It is, however, very difficult to evaluate the extent of that pain. Determining whether a patient such as M is in pain, and if so the degree of that pain, is extremely difficult. Having considered the expert evidence, in particular Professor Turner-Stokes, I conclude that there are times when M experiences pain, and times when she is pain-free. When she feels pain, sometimes she vocalises that experience, at other times not. Sometimes the sounds she makes are an indication of pain, at other times they are not. Consequently, it is very difficult in my judgment to interpret her behaviour as indicative of any particular experience of pain, or the level of pain that she is suffering.

233. Miss Dolan draws my attention to the evidence from the care staff that demonstrates that sensitive and assiduous care by members of staff at the care home seems to ease the symptoms of the pain. Pain relief medication is also available. I accept that M is regularly in pain but conclude that she is not in constant pain, nor does the evidence suggest that she is in extreme pain. Nevertheless, the fact that she is in regular pain, and discomfort and distress, is a factor which must be taken in account when conducting the balancing exercise.

Enjoyment of life

234. Again, Mr Sachdeva invites the court to accept the evidence of Professor Turner-Stokes, supported by members of M's family and some of the carers, that it is difficult to identify anything that causes M pleasure. He submits that there is no clear or corroborative evidence that she can experience pleasure. He acknowledges that pleasant sensations and familiar voices are likely to be positive for her but argues that they are "of a fairly low level of sensory awareness, rather than including any meaningful interaction with the environment." He invites the court to treat with "real caution" any evidence that M smiles. He points out that patients in VS can smile spontaneously. Of course, M is not in VS, but I accept that the evidence of her "smiling" must be treated cautiously. Mr Sachdeva submits that the "broad thrust of the evidence is that at best M's dominant experience may be one of contentment." He submits that the absence of pain, distress or discomfort is not in itself a positive feature.

235. Able-bodied people frequently feel (even if they do not say so) that disability invariably restricts the enjoyment of life. With the growth in understanding about disability in recent years, however, has come an awareness that people with disability often experience profound enjoyment of life, within the limitations that their disability

may impose. It is the arrogance of the able-bodied that, simply because someone is confined to a wheelchair, their enjoyment of life is restricted. On one view, the pleasures of life in such circumstances may appear smaller, but that does not mean they can be disregarded. I do not accept the submission that the absence of pain or discomfort is not in itself a positive feature of life. Comfort and contentment can be, in my view, profoundly positive sensations. Professor Turner-Stoke was inclined to rate "being comfortable" as a neutral experience as opposed to a positive one. I think most people would agree with Mr Badwan that comfort is positive, just as discomfort is negative.

236. The contrast may be more stark where a previously healthy and active person such as M is laid low by illness and becomes severely disabled. Because M is longer able to enjoy life in the way that she was, it is wholly understandable that members of the family think that she does not enjoy life at all. Having considered the evidence of the carers, however, I find that M does enjoy some aspects of her life. I do not accept that her experiences are wholly, or even on balance, negative. Furthermore, in the light of the evidence about her recent outings given by Nurse O and Skills Worker H, I accept the opinion of Miss Gill-Thwaites and Mr Badwan that there is a real prospect that her enjoyment of life may be increased by a programme of stimulation, both inside and outside the home. I recognise the dangers, identified by Professor Turner-Stokes, that M may be sensitive or hyper-sensitive, to such experiences. But the evidence suggests that, with appropriate careful preparation and attention these potentially adverse effects can be overcome as she becomes more familiar with the experience.

237. In short, I do not find that her current life is overwhelmingly negative, or "overly burdensome" in the words of paragraph 5.31 of the Code of Practice, or that there is no prospect of any improvement in the quality and enjoyment of her life.

Prospects of recovery

238. On the other hand, the prospect of any or any significant improvement in M's level of consciousness is remote. I accept Mr Sachdeva's submission, based on all the evidence including a comparison of the two SMART assessments, that there is no evidence that M's level of consciousness has improved over the past eight years. As set out above, Professor Turner-Stokes has changed her assessment as to M's level of consciousness within the MCS spectrum, but the explanation for this change is more likely to be that the professor underestimated the level of consciousness in her initial report rather than any increase in M's awareness in the last few years. The SMART assessments, supplemented by the WHIM test as explained and analysed by Professor Turner-Stokes, give a reasonably clear picture of M's level of consciousness (or as clear as is possible given the difficulties in testing and communicating with M and the inherent difficulties in measuring consciousness in any circumstances). I therefore accept that M is not on the border between VS and MCS, but rather at a moderate level on the MCS spectrum. On this point, I accept the opinion of Professor Turner-Stokes and reject the view of Mr. Badwan that M is at the higher end of that spectrum. She is a long way short of full consciousness and, in all the circumstances, I find it very unlikely that she will ever emerge from MCS.

239. In reaching this conclusion, and expressing it in that way, I acknowledge that there are, as yet, no recognised and defined gradations of consciousness within the MCS spectrum and that the hierarchy of behaviours in the WHIM scale is likely to be

inaccurate in some respects. But I accept the view of the experts that M will very probably remain in MCS for the rest of her life. Given her current life expectancy, it follows that she will remain in this condition for up to ten years. As Mr Sachdeva expressed it in his closing submissions, "after eight years in MCS and with a diffuse non-traumatic brain injury, and in circumstances where M is approaching the end of her life and is therefore experiencing a declining cognitive function, there is no more than a glimmer of hope that M might start to emerge from MCS".

Dignity

240. In all the circumstances, Mr Sachdeva submits that M's dignity will be promoted by the withdrawal of ANH, not by its continued provision and the well intentioned attempts to "normalise" her life in the face of such low prospects of improvement in her awareness.

241. Anyone would wish the end of life to be as dignified as possible. In my judgment, however, there is dignity in the life of a disabled person who is being well cared for and being kept as comfortable and as free from pain as possible, and being provided with the maximum opportunity to extend their enjoyment of life that their disability allows.

Wishes and feelings of family members and carers

242. As set out above, section 4 (7) of the MCA requires the court to take into account the views of anyone engaged in caring for M or interest in her welfare. In this case, the court must take into account, therefore, the views of members of M's family and, in addition, those of members of staff at the nursing home. In particular, the wishes and feelings of S and B are a matter which this court must carefully consider. I accept Mr Sachdeva's submission that the continuation of ANH would cause further distress to them. I agree with him that, while their wishes are obviously not paramount and do not apply as a "stand alone" consideration, they are relevant to the balancing exercise to be carried out under the MCA, not least because they are one of the factors that would have informed M's view about the issue, were she able to consider it.

The balance sheet

243. On behalf of the Applicant, Mr Sachdeva and Miss Butler-Cole submit that the balancing process must be performed in a genuine way by the evidence of M's previously expressed wishes and feelings, and the factors that would have influenced her decision were she able to take it for herself. They contend that her overall quality of wakeful or conscious experiences are predominantly negative because it is likely that she experiences a constant level of background pain and variable hypersensitivity, and does not have truly positive experiences which can be weighed against this, but instead only neutral states of contented wakefulness. When likely wishes and prospects and recovery are weighed in the balance against predominantly negative experience, or predominantly neutral experience, the balance falls in favour of the declaration being granted.

244. On behalf of the PCT, Miss Dolan invites the court to reach the opposite conclusion. When appropriate weight is given to (a) the importance of preserving life; (b) the agreed fact that she is sentient with self and of environmental awareness; (c) the

overwhelming fact of expert evidence that her life is one that, despite her cognitive and physical disabilities, is not without positive elements; (d) the experts' agreement that further steps can be taken to increase the likely positive experiences for her and to reduce her negative experiences; (e) the fact that such pain and discomfort as she does experience can be alleviated by the intervention of carers; (f) her previously expressed wish not to live a life dependent on others (whilst recognising that this statement was not made in the context of the consequences of withdrawing ANH) and (g) the consequence of withdrawal of treatment would be her death by starvation and dehydration in circumstances which would cause her, in all probability, thirst, hunger, discomfort, distress and some pain over a two to three week period, Miss Dolan submits that the balance clearly must come down in favour of continuing to provide ANH to M.

245. As set out above, it is the Official Solicitor's submission that the balance sheet approach is inappropriate in respect of a patient in a MCS who is clinically stable. For the reasons set out above, I do not accept this argument.

246. I adopt the balance sheet approach proposed by Thorpe LJ in *Re: A Male Sterilisation* (supra) and applied in subsequent cases. In my judgment, that process is best expressed in this case by a comparison of the advantages of withdrawing ANH against the advantages of continuing with the treatment.

247. In my judgment, the advantages of the withdrawal of ANH from M can be summarised as follows.

(1) Although M's life will be cut short by up to ten years, she will be freed from the pain and discomfort from which she is currently suffering, and the prospect of increased pain from her chronic conditions.

(2) She will not have to endure any further treatment which could bring significant and unpleasant side effects, nor any other intrusive tests or assessments.

(3) She will be spared years of experiencing further distress such as she demonstrates after seeing S, or hearing certain pieces of music or at other times.

(4) She will be freed from what are described as the indignities of her current circumstances.

(5) Being allowed to die would accord with a number of comments she made prior to her illness as to her wishes and feelings, in particular at the time of the admission of her grandmother, and later her father to nursing homes, and at the time of the Tony Bland case. She has not, however, made any advance decision, nor addressed the specific question whether she would want ANH withdrawn she was in MCS.

(6) By authorising the withdrawal of ANH and thereby allowing M to "die with dignity", the court would be acting in accordance with what family members firmly believe M would have wanted.

(7) Her sister B and her partner S wish ANH to be withdrawn to allow her to die. Their wishes and feelings are based not only on what they believe she would have wanted but also what they generally believe to be in her best interests.

(8) She would be spared further years of life in MCS from which there is no likelihood that she will emerge.

(9) Although she will experience discomfort and possibly pain and distress during the process of withdrawal of ANH, those experiences will be limited in time and can be ameliorated by medication and experienced end of life care.

248. The advantages of continuing ANH are as follows:

(1) M will be kept alive for ten years. The preservation of life is a fundamental principle.

(2) She will be spared the effect of withdrawal of ANH. Even with medication and high quality care, there is a significant risk that the process of dying by starvation and dehydration will cause her pain and distress.

(3) She will continue to experience life as a sensate being with a degree of awareness of herself and her environment.

(4) She will continue to gain pleasure from the things which, as described by her carers, give her pleasure at present – company, listening to conversation, music and the sensory experience of the snoozeroom.

(5) With the introduction of a planned programme of stimulating experience, it is likely that her enjoyment of life can be extended.

(6) If her room is made more comfortable and homely, her immediate surroundings will become more congenial and add to her pleasure in life.

(7) As she is clinically stable, she will continue to experience life at this level for a number of years.

Conclusion

249. In my judgment, the importance of preserving life is the decisive factor in this case.

250. The Applicant's counsel attach very great weight to the various statements made by M as recounted by S and B. As stated above, I accept the veracity of their evidence but I find that those statements were not specifically directed at the question that now arises, namely whether ANH should be withdrawn from her in a minimally conscious state, nor do I find that I can consider those statements as a clear indication some eight years on from the onset of her illness, of what M would now want to happen. Accordingly, while I take her earlier statements into account, I do not attach significant weight to them. I accept that S and B believe that she would want ANH to be stopped, and that they believe the withdrawal of the treatment is in her best interests and would therefore wish that to happen. I take their evidence into account but I do not think it carries decisive weight.

251. Furthermore, I do not agree with Professor Turner-Stokes that M's overall experiences are clearly negative. I accept that her life has a number of negative aspects, but I also find that it has positive elements. On this aspect of the case, I accept the evidence of the carers, who have far greater experience of living with M in recent years than do members of her family whose visits have become less frequent as time has gone by. Like Professor Turner-Stokes, I wondered when I first read the papers whether the carers were over-interpreting M's behaviour, seeing what they wanted to see. Professor Turner-Stokes has come to accept that the carers' accounts are broadly accurate. Unlike Professor Turner-Stokes, I have also the benefit, not only of reading the carers' statements, but also listening to them give oral evidence over a number of days. I have been impressed, indeed moved, by their professionalism and dedication to their demanding job. Although most of them hold a clear view that ANH should not be withdrawn in this case, I find that they have remained objective in the evidence they have given and that their accounts are reliable and accurate. I therefore accept that M does have positive experiences and that, although her life is extremely restricted, it is not without pleasures, albeit small ones. Furthermore, I accept the evidence of Miss Gill-Thwaites and Mr Badwan that there is a reasonable prospect that M's positive experiences and quality of life can be extended by changes to her care plan that carefully expose her to increased stimulation. I am fortified in that belief by the knowledge that such a plan would be implemented by this truly dedicated care team.

252. I have therefore come to the clear conclusion that it would not be in M's best interests for ANH to be withdrawn.

253. I acknowledge again the devotion to M demonstrated by her sister B and partner S, and also by her mother W, who herself is now sadly in very poor health. After pursuing this litigation for years, I know that B and S will be extremely disappointed and probably distressed by my decision. I am sure, however, that they have M's best interests at heart, and I hope that they will be able to contribute to the process of making further decisions about her welfare.

254. So far as the future is concerned, there must be a radical review of M's care plan. I firmly believe that this is a process that should, if possible, be carried out by family members and professionals working together. The Court of Protection is here to help with those endeavours if necessary, but in the first instance, I urge all parties to try to agree a plan for M's future care.

255. I propose that, to underpin the care plan, the court should make a declaration that the current "Do Not Resuscitate" order is continued. It is not disputed that, because of her condition, it would not be in M's interests to receive cardio-pulmonary resuscitation having regard to all the benefits and burdens of such treatments. I accept Mr Sachdeva's submission on this point: "a key factor is the hypoxia that would inevitably result if M's heart were to stop beating and the further damage that such hypoxia would cause to her brain. It is likely that even if CPR were successful, M would be left with worse brain damage and a lower level of consciousness awareness. In making the DNR order weight has been placed on the quality of M's life that CPR might result. Having treatment with the result that M would live in a yet lower level of MCS would not be in M's best interests". So far as other treatment is concerned, including antibiotics, I accept the submission on behalf of the Official Solicitor, supported by the PCT, that such judgments should be left to the treating clinicians, in

consultation with family members and carers. Having decided that ANH should not be withdrawn, and having regard to the fact that M is clinically stable, it is impossible for this court to determine now whether it will be in M's best interests at a future date for specific treatment to be given. That will depend on the circumstances as they arise. Whereas with CPR it is highly probable that any event which require the administration of CPR will cause significant harm to M, so that it is not in her best interests to be resuscitated, the court cannot say at this point whether a specific course of treatment such as antibiotics would at some future date be in her best interests. Whether or not it is in her best interests will depend on the circumstances as they arise, and it must be left to the clinicians to make that decision in consultation with family members having regard to all relevant circumstances.

OBSERVATIONS FOR FUTURE CASES

256. Although some of the older cases concerned patients who whilst diagnosed as being in a VS were probably in a MCS, this is the first case in this country concerning an application to withhold or withdraw ANH from a patient diagnosed as being in a MCS. Professor Turner-Stokes told me that it is reasonable to think that there are several-fold more patients in a MCS than in a VS. The following observations, which have been approved by the President of the Court of Protection, are designed to assist in future applications for the withdrawal of ANH.

257. First, it is important to reiterate that a decision to withhold or withdraw ANH from a person in VS or MCS must be referred to the court: COP Practice Direction 9E, paragraph 5. All applications of this sort must be made to a High Court judge. Furthermore, good practice dictates that they should be allocated at the earliest opportunity to one judge who will be responsible for case management and ultimately conduct the final hearing.

258. Secondly, this case has demonstrated the crucial role played by the formal assessment tools, the SMART and the WHIM. The history of this case shows how cases may be misdiagnosed if these tools are not used. M was initially diagnosed as being in a VS. That led the family, advised by the very experienced clinicians and the independent expert instructed at that stage, to make this application. It was only some time after this application was launched that the SMART test was administered and disclosed that M was in fact in an MCS. I do not know whether or not this application would have been started if that diagnosis had been made at the outset. One can envisage cases, however, in which family members and clinicians take the view that they should start proceedings to withdraw life-sustaining treatment if, but only if, the patient is in a VS. This issue was identified by Seel et al in the 2010 paper cited above:

> "Failure to detect behavioural signs of consciousness may lead to premature termination of treatment and missed clinical opportunities …. Conversely, misinterpreting non-purposeful or reflexive behaviour as conscious behaviour may lead to falsely optimistic prognoses …. In the most severe circumstances, misdiagnosis can cause inappropriate family and legal decisions regarding withdrawal of life-sustaining treatment."

259. It is therefore of the utmost importance that every step should be taken to diagnose the patient's true condition before any application is made to the court. Professor Turner-

Stokes said in evidence that she was "reasonably confident that future guidelines will state that, before making any decision concerning the withholding of ANH, there should be formal testing in the form of the SMART diagnostic test coupled with WHIM tests carried out over a period of time". In future, therefore, no such application for an order authorising the withdrawal of ANH from a patient in VS or MCS should be made unless (1) a SMART assessment (or similarly validated equivalent) has been carried out to provide a diagnosis of the patient's disorder of consciousness and (2) in the case of a patient thereby diagnosed as being in an MCS, a series of WHIM assessments have been carried out over time with a view to tracking the patient's progress and recovery (if any) through the MCS. If an assessment scale becomes validated in the medical literature for tracking a person's recovery through the MCS, this assessment may alternatively be used in place of the WHIM.

260. Thirdly, given the fundamental issues involved in cases involving the withdrawal of ANH, it is alarming to the court that public funding has not been available to members of the family to assist them in prosecuting their application. In the event, the Applicant's team has acted *pro bono* throughout the hearing and during much of the very extensive preparation. I stress that this has not caused any disadvantage to the Applicant. As I said at the conclusion of Mr. Sachdeva's submissions, the family could not have had better representation. But it is intolerable that the family should have been dependent on the willingness of lawyers to work without remuneration. In this case, the "playing-field" was level because of the exceptional generosity of the Applicant's lawyers. In other cases, members of a family who wished to ask the court to authorise the withdrawal of ANH but did not qualify for means tested public funding may have to appear in person, given the very high costs of litigation. Such a situation would seem to infringe the family's rights under Article 6 of ECHR. There are many demands on the restricted legal aid budget, but consideration should be given to extending the right to non-means tested public funding to family members seeking to bring this type of application. At present, such non-means tested funding is available to parents whose children are the subject of care proceedings under the Children Act 1989. That provision is justified by the fundamental and life-changing consequences which flow from the making of a care order. The same argument applies to applications for the withdrawal of artificial nutrition and hydration.

261. Finally, the hearing of the application has vindicated the decision, made for the reasons set out in the earlier judgment reported at [2011] EWHC 1197 (COP), to conduct the hearing in open court but subject to a reporting restriction order that prevents identification of M, family members, and the care home and its staff. Provided that the privacy of the individuals involved is fully respected, it is imperative that the press should be as free as possible to report cases of this sort. The issues involved are of fundamental importance to all of us, both collectively and individually. For society as a whole, they touch upon the very challenging issues, currently the subject of much public debate, about the treatment of those suffering from severe disability, and those nearing the end of their lives. For each of us as individuals, they draw attention to the question of how we would wish to be treated should we find ourselves in a vegetative or minimally conscious state. The public needs to be informed about how such questions are resolved, be it under the advance decision procedure in sections 24 to 26 of the Mental Capacity Act or by application to the Court of Protection. It is therefore in the public interest for such cases to be

reported as widely and freely as possible, provided that due respect is paid to the wishes of the family to protect their privacy.

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