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Case No: COP12621732

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26/06/2015

Before :
MR JUSTICE NEWTON
- -
Between :

St George's Healthcare NHS Trust	**Applicant**
- and -	
P **(by his litigation friend, the Official Solicitor)**	**First Respondent**
- and –	
Q	**Second Respondent**

- -
- -

Parishil Patel (instructed by **Hempsons**) for the **Applicant**
Bridget Dolan (instructed by **The Official Solicitor**) for the **First Respondent**
Vikram Sachdeva QC (instructed by **Irwin Mitchell**) for the **Second Respondent**

Hearing dates: 26, 27, 31 March and 11-12 June 2015
- -

Judgment

MR JUSTICE NEWTON

The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the incapacitated person and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Newton:

Introduction and Background

1. On 28 November 2014 P suffered a major cardiac arrest. There was a period of 25 minutes between his arrest and spontaneous circulation being restored. Tragically he had by then suffered hypoxic brain damage such that he is left with a profound and prolonged disorder of consciousness. Since then he has been wholly dependant on the ICU (intensive care unit) for all aspects of his care.

2. On 20 January 2015 the Health Trust responsible for his care made an application seeking declarations in this very serious medical case. They seek declarations:

i) That he lacks capacity (this is uncontentious);

ii) That it is not in his best interests to receive cardio pulmonary resuscitation (CPR) in the event of cardiac arrest (this is also now uncontentious); and

iii) As to whether it is lawful to continue to provide renal replacement therapy (RRT), the Trust wish to discontinue life sustaining treatment with the inexorable and inevitable consequence that as a result P would quickly die.

3. I have already had a number of hearings in this case including handing down a judgment on 13 March 2015, [2015] EWCOP 15, concerning the issue of giving notification to the press prior to a reporting restrictions order being made.

Capacity

4. Capacity is not in issue between the parties. The unanimous clinical and expert opinion is that due to his severe brain injury P lacks capacity within the meanings of sections 2 and 3 of the MCA to make decisions regarding his medical treatment and litigation. Section 2(1) provides:

> "For the purposes of this Act a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain."

5. Section 3(1) of the MCA provides:

> "(1) For the purposes of section 2 a person is unable to make a decision for himself if he is unable: (a) to understand the information relevant to the decision; (b) to retain that information; (c) to use or weigh that information as part of the process of making the decision; or (d) to communicate his decision (by talking, using sign language or any other means)."

6. Section 4(3) of the MCA provides that when making any decision for those lacking capacity it must be considered whether it is likely that the person will at some time have capacity in relation to the matter in question. The uncontested expert and clinical evidence is that it is unlikely that P will ever regain capacity.

7. The essential foundation stone of the application made within weeks of the hypoxic brain injury sustained by P at the end of November 2014 was that he was on balance considered by the treating clinicians to be in a permanent vegetative state (VS). The relationship between the Trust and the family has very unfortunately become increasingly polarised. Having regard to the extreme nature of the consequences of the issue with which they were grappling that is hardly surprising. However, it is regrettable having regard to P's welfare and future that that situation has arisen. The family are collectively and individually impressive, being both intelligent and articulate, educated as well as very well informed. The family have consistently maintained their position that P is in a minimally conscious state (MCS) and that they have continued to witness purposeful responses from P. They strongly contend that

the discontinuance of treatment would be against his personal (as well as his religious) views, and in any event not in his best interests. I have found the increasingly polarised view of the parties profoundly troubling. The family have always properly and steadfastly maintained and argued their position. But for their politely and cogently articulated stance, it may well have been that renal replacement therapy would have been stopped, and P would already no longer be alive. They endeavoured to support their efforts by the taking of video recordings of occasions when they said that P had responded to verbal communication. That position was strongly opposed by the Health Trust who contended concern about the privacy and dignity of other patients and offered the services of the Trust's medical photographer. Surprisingly the Court was required to make a decision that they were (a) able to do so and (b) could rely in Court on those recordings. In fact those video recordings provided a watershed insight to the proper conclusion in this case. As I say, but for their persistence, and the consequent anxiety of the Official Solicitor I could have so easily concluded on inadequate evidence, as it transpired, a conclusion that would have led to P's demise.

8. This case is yet another stark example of the absolute necessity for a structured assessment to have occurred before any application is even contemplated. I have been told in this and in other cases that misdiagnosis (of people who are said to be in a vegetative state but are in truth in a minimally conscious state) occurs in a remarkably high number of cases, the rate of misdiagnosis is said to be some 40%. That is not to say that in any way any male fides attaches to the treating clinicians. In this, as in every other case which I have heard, I have the utmost respect both as a human being and as a professional judge to the care with which they apply themselves, to these most difficult issues of which this is just such an example. Without a rigorous evidential analysis real mistakes can be made.

The Hearing

9. The hearing has lasted five days over a considerably adjourned period, judgment being delivered on the 6th. It is a very unsatisfactory way of conducting such a hearing. Having seen the very powerful and affecting video recordings of P myself on day 3 it became abundantly clear that further and proper assessment and enquiry was absolutely necessary and essential. As a result Helen Gill-Thwaites, a specialist occupational therapist, continued and carried out the further assessment using the internationally respected assessment process known as SMART. Additionally Mr Derar Badwan, a leading expert in neuro rehabilitation directed the optimum circumstances for that and his own subsequent opinion to be investigated and formulated. Their united opinion and evidence was that at this stage of assessment it was clear, as the family had always contended, that P was in a minimally conscious state. I confess I am very troubled that in apparent response to that expert opinion the Trust's reaction (without issuing a further application) was to apply to withdraw a whole raft of other treatments. That inexplicable development seemed to me at best to illustrate the widening the gulf between the family and those who were treating P, at best a hardening of mind. That view was fortified further when it subsequently emerged during the course of evidence (when Dr Dewhurst resumed evidence) that Dr Khan, the consultant neurologist responsible for P's treatment, had recently changed his mind and now considered that P was in a minimally conscious state and had emailed that view to the Trust's solicitor. All counsel seemed unaware of that

development; certainly the Court was, and it is disappointing that this important information should in fact surface in this way. I do not think this represents bad faith but a reflection of the litigation as a whole. As I have already made clear I do not doubt the very great sincerity of the consultants involved in the care of P, but having regard to the Court's strong presumption in preserving the sanctity of life and of the overarching principle that should be borne in every case with this background it was a surprising development. The law regards the preservation of life as a strong fundamental principle.

10. Having considered all the circumstances I have come to the firm conclusion, indeed almost inevitable conclusion, that it is not in P's best interests for renal replacement therapy (RRT) to be withdrawn. Indeed quite the contrary, that it is lawful and necessary that it should be continued. Having regard to the evidence now available, if the facts known today were known in January I anticipate that this application might never have been issued. It is surprising in a way that it is persisted with in the light of what seems to me the incontrovertible and strong evidence now available.

Background

11. P was born in the mid 1970s to a close, highly supportive and impressive family. He was born with a dysplastic kidney which means that one of his kidneys was not properly formed. The family were aware that at some stage P would probably become unwell in the future but he was healthy until his thirties. In 2007 he became unwell and required treatment for kidney failure He began both dialysis and occasionally hemofiltration. It is clear he struggled with both. The treatments had a significant effect on his wellbeing, he was considerably exercised by the circumstances of their application. He looked to alternatives including transplantion. Much has been made during the course of the hearing of his failure to comply with the strict regime of dialysis three times weekly. He generally only attended twice. I heard considerable evidence about discussions concerning the need for more regular attendance for dialysis. His non compliance however was not straightforward. He clearly investigated every alternative and was very anxious about the experiences of the patients at the various medical institutions. He considered the circumstances to be far from hygienic, he was aware that patients were frequently exhausted and considered the whole process deeply undignified. A secondary aspect of dialysis occurring only twice a week was that the occasions between dialysis being longer there was a relatively longer period when he felt less exhausted, or at least relatively well or at least tolerably so. He was very affected when two young patients died and considered whether rightly or not that that was as a result of a failure in hygiene. He made worldwide investigations into alternative therapy. There is conflicting evidence as to whether he actually went to China, but it is evident that he certainly considered such a trip, it being an indication of the importance which he attached to his health and wellbeing endeavouring to identify a different way of dealing with his treatment. In addition he investigated transplant. I heard a considerable amount of evidence on this aspect and in particular the Court being invited to consider his inconsistent and neglectful care (as it was submitted). In the end if this aspect was determinative I would not find this aspect helpful to the Trust's case having regard to the strong and powerful diagnosis available to the Court and the strong and incontrovertible evidence available from the family, all of which points to one direction and to one almost inevitable conclusion.

The Issues

Diagnosis – what is P’s level of consciousness?

12. The issue of diagnosis is crucially fundamental to the examination of P’s future. Clearly if he is and remains in a permanent vegetative state the principles by which the Court will examine his future are different. CT scans occurred in December, January and March and according to the clinical team show progressive atrophy of the brain, i.e. neuronal death and extensive and irreversible brain damage. However, Mr Badwan does not consider that CT scanning is optimal and additionally that there needs to be global and holistic sequential and rigorous assessment and recording over a much longer timeframe. Having said all that, there is little dispute between the experts that the prognosis for P is that he is unlikely ever to make a full recovery.

Provision of renal replacement therapy

13. If P is in VS, and there is no real prospect of recovery, then it would not be in his best interests to continue treat him (because a person in a continuing vegetative state has no interests and therefore no best interests). However, if he is in a minimally conscious state then the issue to be considered must be on the balance of best interests in accordance with section 4 MCA and the appropriate professional guidance.

The Law

14. Section 1(5) MCA provides:

> “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.”

15. Section 4 MCA sets out the factors which must be taken into account by the person making the “determination” for these purposes the Court.

> (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.
>
> (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 as far as 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 practical or appropriate to consult them the views of – (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind; (b) anyone engaged in caring for the person or interested in his welfare; (c) any donee of a lasting power of attorney granted by the person; and (d) any deputy appointed for the person by the court, as to what would be in the person's best interests and in particular as to the matters mentioned in subsection 6.

16. The Court when applying section 4 MCA must therefore make its own independent assessment of best interests applying a strict level of scrutiny to the evidence as a whole. The evaluation of best interest is performed by the Court on the basis of all the evidence, it is not confined to the medical assessment of best interests. Account must be taken of the evidence of the treating clinician, the family and the independent experts. The Court is the final arbiter, this being yet another circumstance in which Parliament has devolved this, the most difficult of any decision, to an individual - the judge.

17. In answering those questions I apply paragraph 5(3)(1) of the MCA Code of Practice and ask myself whether the treatment is futile, overly burdensome to the patient or whether there is no prospect of recovery (in the sense of the resumption of a quality of life which P would regard as worthwhile).

18. I particularly bear in mind

> "Best interests must be given a generous interpretation … 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:" per Hedley J in Portsmouth NHS Trust v Wyatt [2005] 1 WLR 3 995.

19. Each case of course turns on its own facts and I have had brought to my attention for example the case of Lincolnshire NHS Trust v N [2014] EWCOP 16, of 21 July 2014, a decision of Mrs Justice Pauffley. In relation to my application of the principles I in particular draw heavily on the decision of the Supreme Court in Aintree University Hospitals NHS Foundation Trust v James and others [2013] UK SC 67. In the lead opinion given by Baroness Hale of Richmond who reviewed and set out section 4 MCA then continued as follows at paragraph 24:

> "24. This approach follows very closely the recommendations of the Law Commission in their Report on Mental Incapacity (1995, Law Com No 231) on which the 2005 Act is based. It had been suggested in Re F that it might be enough if the doctor had acted in accordance with an accepted body of medical opinion (the Bolam test for medical negligence). However, as the Court of Appeal later recognised in Re S (Adult Patient: Sterilisation) [2001] Fam 15, there can only logically be one best option. The advantage of a best interests test was that it focused upon the patient as an individual, rather

than the conduct of the doctor, and took all the circumstances, both medical and non-medical, into account (paras 3.26, 3.27). But the best interests test should also contain "a strong element of 'substituted judgment'" (para 3.25), taking into account both the past and present wishes and feelings of patient as an individual, and also the factors which he would consider if able to do so (para 3.28). This might include "altruistic sentiments and concern for others" (para 3.31). The Act has helpfully added a reference to the beliefs and values which would be likely to influence his decision if he had capacity. Both provide for consultation with carers and others interested in the patient's welfare as to what would be in his best interests and in particular what his own views would have been. This is, as the Explanatory Notes to the Bill made clear, still a "best interests" rather than a "substituted judgment" test, but one which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie. To take a simple example, it cannot be in the best interests to give the patient food which he does not like when other equally nutritious food is available.

25. Section 4(5) and (10) was an addition while the Bill was passing through Parliament: in considering whether treatment which is necessary to sustain life is in the patient's best interests, the decision-maker must not be motivated by a desire to bring about the patient's death. Like much else in the Act, this reflects the existing law.

26. Beyond this emphasis on the need to see the patient as an individual, with his own values, likes and dislikes, and to consider his best interests in a holistic way, the Act gives no further guidance. But section 42 requires the Lord Chancellor to prepare a code or codes of practice for those making decisions under the Act. Any person acting in a professional capacity or for remuneration is obliged to have regard to the code (section 42(4)) and a court must take account of any provision in or failure to comply with the code which is relevant to a question arising in any civil or criminal proceedings (section 42(5)).

27. The Mental Capacity Act Code of Practice was published in 2007. Lord Pannick QC, on behalf of the trust, accepts that if there is any conflict between what it says and what is said in the guidance given by the General Medical Council under section 35 of the Medical Act 1983 (Treatment and care towards the end of life: good practice in decision-making, 2010) or by the British Medical Association (Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision-making, 3rd edition 2007), then the Mental Capacity Act Code must prevail.

28. The Mental Capacity Act Code deals with decisions about life-sustaining treatment in this way:

"5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. 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.

5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interest's 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.

5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. 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." (Emphasis supplied.)

29. It is important to read these paragraphs as a whole. As paragraph 5.33 makes clear, doctors have to decide whether the life-sustaining treatment is in the best interests of the patient. Section 4(5) does not mean that they have to provide treatment which is not in the patient's best interests. Paragraph 5.31 gives useful guidance, derived from previous case law, as to when life-sustaining treatment may not be in the patient's best interests. Both the judge and the Court of Appeal accepted them as an accurate statement of the law and so would I. However, they differed as to the meaning of the words in italics. The Code is not a statute and should not be construed as

one but it is necessary for us to consider which of them was closer to the correct approach.

30. In concluding that he was not persuaded that treatment would be futile or overly burdensome or that there was no prospect of recovery, Peter Jackson J said

“(a) In Mr James’ case, the treatments in question cannot be said to be futile, based on the evidence of their effect so far.

(b) Nor can they be said to be futile in the sense that they could only return Mr James to a quality of life which is not worth living.

(c) Although the burdens of treatment are very great indeed, they have to be weighed against the benefits of a continued existence.

(d) Nor can it be said that there is no prospect of recovery: recovery does not mean a return to full health, but the resumption of a quality of life that Mr James would regard as worthwhile. The references, noted above, to a cure or a return to the former pleasures of life set the standard unduly high”.

…

35. The authorities are all agreed that the starting point is a strong presumption that it is in a person's best interests to stay alive. As Sir Thomas Bingham MR said in the Court of Appeal in Bland, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy". Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.

36. The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and every case, is different and must be decided on its own facts. As Hedley J wisely put it at first instance in Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 FLR 21, "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" (para 23). There are cases, such as Bland, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time.

37. Nevertheless, there has been some support for a "touchstone of intolerability" in those cases where a balancing exercise is to be carried out. In Re B (A Minor) (Wardship: Medical

Treatment) [1981] 1 WLR 1421, authorising an operation which was necessary to save the life of a baby with Down's syndrome, Templeman LJ said that the question was whether "the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die", and Dunn LJ said that there was "no evidence that this child's short life is likely to be an intolerable one". Taylor LJ, in Re J (Wardship: Medical Treatment) [1991] Fam 33, also adopted a test of whether life would be intolerable to the child. However, Lord Donaldson and Balcombe LJ did not see "demonstrably so awful" or "intolerable" as laying down a quasi-statutory test which would apply in all circumstances. And in Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181, [2005] 1 WLR 3995, the Court of Appeal considered that observations on "intolerability" in W Healthcare NHS Trust v H [2005] 1 WLR 834 were obiter, given that the judge had correctly "decided the case by a careful balance of all the factors in the welfare equation" (para 84).

38. In Re J, Lord Donaldson stated that account had to be taken of the pain and suffering and quality of life which the child would experience if life were prolonged and also of the pain and suffering involved in the proposed treatment. Here we can see a possible genesis for the references in the Code of Practice to the "prospect of recovery" and the "overly burdensome" nature of the treatment. Similarly in Bland, Lord Goff referred to the class of case where "having regard to all the circumstances (including the intrusive nature of the treatment, the hazards involved in it, and the very poor quality of life which may be prolonged) it may be judged not in the best interests of the patient to initiate or continue life-prolonging treatment" (p 868). But he expressed no view as to the precise principles applicable to such cases, because Anthony Bland's case was in a different category, where the treatment was of no benefit to him at all. Here there was no weighing operation to be performed because treatment was useless: "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 (p 869)". Here we can see a possible genesis of the word "futile" in the Code of Practice and in that case it referred to treatment which was of no benefit at all to the patient.

39. The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what

the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.

40. In my view, therefore, Peter Jackson J was correct in his approach. Given the genesis of the concepts used in the Code of Practice, he was correct to consider whether the proposed treatments would be futile in the sense of being ineffective or being of no benefit to the patient. Two of the treatments had been tried before and had worked. He was also correct to say that "recovery does not mean a return to full health, but the resumption of a quality of life which Mr James would regard as worthwhile". He clearly did consider that the treatments in question were very burdensome. But he considered that those burdens had to be weighed against the benefits of a continued existence. He was also correct to see the assessment of the medical effects of the treatment as only part of the equation. Regard had to be had to the patient's welfare in the widest sense, and great weight to be given to Mr James' family life which was "of the closest and most meaningful kind".

41. Perhaps above all, he was right to be cautious about making declarations in circumstances which were not fully predictable or fluctuating. The judge was invited to address the question whether it would be lawful to withhold any or all of these treatments. But if he had been asked the right question, whether it would be in the patient's best interests to give any or all of them should the occasion arise, his answer would clearly have been to the same effect. He would have said, as he was entitled to say that, on the evidence before him, it was too soon to say that it was not. That conclusion is quite consistent with his statement that "for what it is worth" he thought it unlikely that further CPR would be in the patient's best interests.

42. That is not to say that I would have reached the same conclusion as the judge in relation to each of these treatments. There was no question of withdrawing clinically supported nutrition and hydration or ventilation or other supported breathing or, by the time of the hearing, intravenous antibiotics. The treatments in question were all highly invasive. I might have drawn a distinction between them. Invasive support for circulatory problems had been used successfully in the past and the patient had rallied. Renal replacement therapy had not so far been needed and so it might be difficult to predict both its effectiveness and its impact upon the patient's overall wellbeing. Cardiopulmonary resuscitation, on the other hand, although it had been used successfully in the past, is designed

to restart a heart which has stopped beating or lungs which have stopped breathing, in effect to bring the patient back to life. I can understand why the judge thought it premature to say that it should not be attempted. But given the particular nature of this treatment, given its prospects of success, and particularly given the risk that, if revived, the patient would be even more seriously disabled than before, I would probably have declared that it would not be in the patient's best interests to attempt it. But if the judge has correctly directed himself as to the law, as in my view this judge did, an appellate court can only interfere with his decision if satisfied that it was wrong: Re B (A Child) (Care Proceedings: Appeal) [2013] UKSC 33, [2013] 1 WLR 1911. In a case as sensitive and difficult as this, whichever way the judge's decision goes, an appellate court should be very slow to conclude that he was wrong.

43. It follows that I respectfully disagree with the statements of principle in the Court of Appeal where they differ from those of the judge. Thus it is setting the goal too high to say that treatment is futile unless it has "a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering". This phrase may be a partial quotation from Grubb, Laing and McHale, Principles of Medical Law (3rd edition 2010), para 10.214, where the authors suggest that "Treatment can properly be categorised as futile if it cannot cure or palliate the disease or illness from which the patient is suffering and thus serves no therapeutic purpose of any kind". Earlier, they had used the words "useless" or "pointless". Given its genesis in Bland, this seems the more likely meaning to be attributed to the word as used in the Code of Practice. A treatment may bring some benefit to the patient even though it has no effect upon the underlying disease or disability. The Intensive Care Society and the Faculty of Intensive Medicine, who have helpfully intervened in this appeal, supported the test proposed by Sir Alan Ward. But this was because they believed that it reflected clinical practice in which "'futility' would normally be understood as meaning that the patient cannot benefit from a medical intervention because he or she will not survive with treatment". That is much closer to the definition adopted by the judge than by Sir Alan.

44. I also respectfully disagree with the statement that "no prospect of recovery" means "no prospect of recovering such a state of good health as will avert the looming prospect of death if the life-sustaining treatment is given". At least on the evidence before the judge, this was not, as Sir Alan Ward put it, a situation in which the patient was "actively dying". It was accepted in Burke (as it had been earlier) that where the patient is close to death, the object may properly be to make his dying as comfortable and as dignified as possible, rather than to take

> invasive steps to prolong his life for a short while (see paras 62-63). But where a patient is suffering from an incurable illness, disease or disability, it is not very helpful to talk of recovering a state of "good health". The patient's life may still be very well worth living. Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities. As was emphasised in Re J (1991), it is not for others to say that a life which the patient would regard as worthwhile is not worth living.
>
> 45. Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.”

20. Clearly diagnosis will determine whether or not an assessment of P’s best interests is even required.

21. The RCP (Royal College of Physicians) Guidelines suggest that a state of VS arising from hypoxic injury should only be classified as permanent once six months has elapsed. Those are guidelines for clinical practice (not followed in the US where the guideline is three months), six months has now elapsed (if only just). In any event the Court takes an individualised approach to the patient at the heart of the case, so once diagnosis is established then the Court will go on to consider the clinical evidence in relation to prognosis, and address those in an individual’s case rather than by reference to the generic and global guidelines.

The Evidence

P’s present condition

22. Dr Crerar-Gilbert is one of the treating consultant intensivist. She described P in the end stage renal failure requiring regular dialysis. He also suffered with hypertension, anaemia and hyperparathyroidism. She considered that he had suffered a cardiac

arrest and hypoxic brain injury because of the high potassium level in his blood which was a direct result of him attending dialysis only twice weekly.

23. Dr Jones was P's treating consultant nephrologist since 2008. He recounted his poor compliance with renal treatment choosing not to follow medical advice as to the frequency of required dialysis. He was not well enough medically to be considered for a transplant. He gave evidence of limited life expectancy, perhaps 12 months.

The earlier diagnosis of P's consciousness

24. Dr Crerar-Gilbert concluded that P was in a deeply unconscious state with no conscious awareness or experience. She concluded that there was no potential for meaningful recovery. On the basis of her clinical assessment, combined with the CT scans and the EEG results, she said that he was in PVS/minimally conscious state.

25. At best his eyes opened to stimulus but she could not say whether that was reflective or a purposeful response. Her view that he was in such a lowered state of consciousness that he was unlikely to be in significant pain or experience anything like pain or discomfort was generally shared by all the doctors. On prognosis Dr Crerar-Gilbert concluded that the consequence of lack of blood supply to the brain was tissue damage and cell death. Such damage and death is irreversible, there is no potential for regeneration.

26. Dr Khan, the consultant treating neurologist has reviewed P on repeated occasions. He diagnosed P as being in a minimally conscious state (at the lower end) on 9 December 2014 but revised his diagnosis later in December to one of PVS. Dr Khan described serial investigations into P's CT brain imaging, stating that it showed progressive brain atrophy. He therefore considered that his conclusion was permanent, as neuronal loss could not be replaced. He considered that there was no prospect of meaningful recovery or at least it was highly improbable … by which he meant that there was no potential or chance that consciousness would improve from its current state and may well deteriorate further (a view shared by Dr Edsell, Dr Nawf Al-Subaie and Dr Doberenz). Subsequently (very recently) he has revised his opinion again having seen the substantial video recordings prepared by the family for the independent experts.

The current evidence of diagnosis of P's disorder of consciousness

27. The jointly instructed experts, Mr Badwan and Ms Gill-Thwaites, commenced their enquiries in the earlier part of this year. However, in her report dated 9 June Ms Gill-Thwaites describes how she observes P: "demonstrated an ability to follow motor instruction, albeit inconsistently and often delayed, requiring a great deal of rousing, verbal instruction and encouragement. However two responses over the 10 sessions were immediate. He also localised a voice on his left side.

> "In a functional communication modality he demonstrated possible communicative facial expressions to familiar conversations and topics."
>
> "… A different expression was seen during discussions of a familiar nature and was felt to be an expressive, communicative

> response. It was not possible to understand what emotion he was expressing."

All those recordings demonstrate some conscious awareness and were therefore indicative of MCS.

28. Mr Badwan's initial report on 10 February 2015 considered on the information then made available to him that the diagnosis of VS was probably correct. However, he noted the urgent need for further SMART testing, especially since the records recorded reports of P frowning and of the possibility of obeying verbal instruction. In his subsequent report in March 2015, made available for the first part of the hearing, Mr Badwan reviewing the findings of the SMART testing so far and clinical assessments concluded that P was presently either at the lower limits of minimally conscious state or in a vegetative state. On balance he considered at that stage that it was more likely the latter. The viewing of the video recordings prepared as part of the "treatment" phase of SMART made a significant impact on Mr Badwan's assessment. That assessment was independent of and prior to reading the final report of Ms Gill-Thwaites. He identified several occasions on which P appeared to (i) anticipate an action or a process and act upon it; (ii) obey verbal commands.

29. Given that evidence Mr Badwan firmly concluded that P shows higher cognitive functioning "beyond that which is seen in a vegetative state". Although the behaviours are highly inconsistent, and at times preceded by delay, they nonetheless are consistent with a diagnosis of minimally conscious state.

30. I have already adverted to some of the equivocal opinion within the treating consultants, both from Dr Crerar-Gilbert and others. Dr Khan, the neurologist, having reviewed P on many occasions, initially diagnosed a minimally conscious state and then a persistent vegetative state. More recently it appears, particularly having regard to his later review of the most recent videos taken in May 2015, Dr Khan has said "I would agree with Mr Badwan and Ms Gill-Thwaites that there are signs suggesting P is in a MCS." He remains of the view that it is at the severe end of the spectrum in that regard.

31. Dr Dewhurst, whose care and anxiety concerning P could not be doubted, recognised that the differentiation of persistent disorders of consciousness is a matter outside his own expertise (he is a consultant intensivist) and therefore he would bow down to other expert opinion on diagnosis.

32. It is now overwhelmingly clear on the evidence that P is in a minimally conscious state. That is the view now held by both the independent experts who have particular special expertise in diagnosing disorders of consciousness: Ms Gill-Thwaites, Mr Badwan and also Dr Khan, heading the treating team, as having particular neurological expertise. That diagnosis of MCS also accords with the accounts of the family who have believed and asserted from the outset that they have achieved purposeful responses from P at all times.

The Best Interests Analysis – renal replacement therapy

33. Pursuant to section 4 of the Mental Capacity Act 2005 the burdens of life have to be weighed by the Court against the benefits of continued existence (see Re M [2012] 1 WLR 1653).

34. A suggested balance sheet of matters arising from the evidence which appear to be relevant has been helpfully provided through the Official Solicitor. I bear in mind of course that when considering the weight to be attached to the various factors a primary consideration and lodestone is the principle of sanctity of life which whilst not absolute must always weigh heavily in the balance. Furthermore, in determining what weight to give to the various factors in favour of or against life preserving treatment particular considerations arise from the MCA Code of Practice as endorsed by Aintree. Those are particularly whether the proposed treatment is futile (in the sense of being ineffective or being of no benefit to the patient), overly burdensome to the patient and or whether there is no prospect of recovery.

Is treatment futile?

35. It does not appear to be in question that but for P's brain injury the renal replacement therapy would be offered to him. There is of course no doubt that his kidney failure is not reversible and as to his unsuitability for future transplant. I was struck when Dr Dewhurst told me in evidence that had P left clear instructions before his injury saying that he wished to be kept alive in his present condition then the clinical team would continue to provide him with renal replacement therapy. In those circumstances it is difficult, indeed impossible, to see how any treatment could be considered to have no therapeutic purpose if the Court is satisfied that it is what the patient would have wanted. Indeed as Dr Dewhurst's oral evidence developed in the adjourned hearing it became clear that the basis for the application to withdraw treatment was not the futility of the treatment but the treating team's belief that continued treatment was not what P would want. I was struck by the care and thought that Dr Dewhurst had applied to this, including whether he would wish to be in that position himself, or thinking about the condition of his own son if he were in this position. Whilst that thought process seems to me completely understandable it is not relevant to my consideration under this head, since the test is futility, and there is no doubt that it is not futile, since it keeps P alive.

How burdensome is treatment?

36. Quite obviously if P's life is full of discomfort and pain without any pleasure or comfort may well be considered burdensome. It is evident on the evidence that P's MCS puts him at a low level of consciousness such that there is little evidence that in fact he experiences pain. I was told by Mr Moore, an impressive specialist nurse, in March that many staff interpret facial expressions and assume the grimace is pain. Mr Badwan told me he has not required analgesia more than paracetamol and Dr Dewhurst said that the neurologists believe that it is unlikely that P can feel pain. Whilst I do not rule out that P can feel discomfort or pain the evidence is clear that I could not possibly be satisfied that P experiences such a degree of pain that might justify non-continuance of essential life prolonging treatment. It is in short not particularly onerous, the balance is all one way.

Is there no prospect of recovery?

37. In respect of the prospect of recovery the experts and the clinicians agree that the prognosis for P in terms of his prospects of functional recovery is poor. Dr Khan in March said that there "is no prospect of meaningful recovery. By that I mean that there is no chance consciousness will improve from its current state. He may well deteriorate further." Mr Badwan could not yet rule out the possibility of a further increase in consciousness. His initial views were also that P would not likely recover from his present condition and the prospects of recovery were remote. The evidence is stark given that the extensive brain damage shown on the scans demonstrates that it is unlikely, as the doctors agree, that he will return to an independent life. However, Mr Badwan posed three possible scenarios: (1) that his consciousness could have been VS and is now MCS; (2) the observations that we are seeing now are what the family have observed before; or (3) he is exactly the same but that does not mean that we have yet got recordings over a period of time or for that he is in fact deteriorating. Mr Badwan was very concerned that the SMART assessment had yet to be conducted at intervals, so that the trajectory of his condition could be scientifically and evidentially analysed and assessed. Self evidently P suffers from a spectrum of difficulties but even so Mr Badwan was unable to give any prediction of the likelihood of trajectory, whether that be improvement or deterioration. Every patient is self evidently different. He was anxious about the CT scans which were put to him in cross-examination, pointing out that the best evidence for assessment in these very difficult circumstances is by the carrying out of an MRI rather than a CT scan, so that proper differentiation can then be made possible. Here (as the Supreme Court held in Aintree) the concept of no prospect of recovery is not to be equated with having the prospect of a return to good health. The essence is whether a patient can resume a quality of life which they would regard as worthwhile.

> "Where a patient is suffering from an incurable illness, disease or disability, it is not very helpful to talk of recovering a state of "good health". The patient's life may still be very well worth living. Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities."

As was emphasised in Re J [1991] it is not for us to say that a life which the patient would regard as worthwhile is not worth living.

Wishes and feelings, values and beliefs

38. The quality of life should be judged not by the values of others but from the particular perspective of the patient. In considering what the patient himself might regard as worthwhile P's prior statement and behaviours as they can be discerned from his family, his wishes, his beliefs, his feelings and his values are all relevant. Prior to his loss of capacity P had made no valid or applicable advance decision dealing with medical treatment generally or the withdrawal of life sustaining specifically, nor did he create any lasting power of attorney. However, the very strong available evidence from P's family and friends is highly relevant in my application of section 4(6) and section 4(7) of the MCA. This includes:

(1) prior to his injury he told his cousin that he did not agree that people should be assisted to die, and that a life was no less valuable or less worth living if a person was chronically disabled or ill. That was powerfully confirmed by his cousin in evidence.

(2) P was a deeply religious man. He strongly believed that life was sacred given by God and could only be taken away by God.

(3) As a Sunni Muslim he believed that suffering was a component of predestination and someone else should not play an assisting role in shortening life merely because of the subjective quality of that life. It is against the tenet of his faith to do anything to shorten a life.

(4) He had powerful wishes and feelings which were well expressed and which should not be supplanted or substituted by anyone else's view. In that regard, for example, Dr Dewhurst very carefully balanced how he or others in his perspective might feel there could be no question of his professionalism or compassion but the real test is the evidence which demonstrates directly what known about P himself.

(5) P was said to have rejected dialysis perhaps because of a cavalier or neglectful approach. In fact the evidence seems to me to suggest precisely the contrary. It was not for any lack of concern for his health but concern about his well being, whether it be hygiene at the hospital or the seeking of some other alternative method of treatment.

(6) It is evident from all the evidence that he wanted to receive the best possible treatment for his kidney condition in order to improve and ensure his chances of survival.

All those matters point strongly to P wishing to ensure that life preserving treatment should continue whatever may befall him.

39. As I have already mentioned Dr Jones, who was involved in P's care for several years, took the view that P would not wish for an existence dependent on such increased levels of care as now. Additionally Mr Moore pointed to the most undignified existence that a patient must necessarily have when nursed in ICU and suggested that that was not an existence that most people would tolerate, let alone welcome, when there is so little prospect of functional recovery.

40. In looking at those aspects and as to whether or not P would assess his life as being regarded as worthwhile I attach far more weight to the relevant expressions of his articulate and well informed family members and friends who have direct knowledge of P's pre-injury knowledge, understanding and philosophy, in particular those who know about his beliefs and values.

41. In the light of his previously expressed strong views, coupled with his strong religious beliefs, the weight of the evidence all falls heavily to one side which is that the preservation of any life would be considered by P to be of significant value. His present circumstances are a life which P would find worthwhile, even though I entirely accept many others would not adopt the same position.

42. Finally, even though full emergence from MCS is not anticipated as a result of the degree of neurological injury, given the diagnosis, and the lack, so far of proper evidential evaluation over time, it cannot be discounted that there might yet be further improvement in the level of his consciousness. P already shows a marked different response to his family (than to professionals) and that might suggest that he recognises them, and draws comfort from their activities and presence. He clearly responds to the love and affection which they show him. It would therefore be absolutely premature on any view to find that there could yet be no improvement in the quality of the experience of life for P. Mr Badwan gave additional evidence about the future treatment and care of P.

Conclusions

43. In weighing the differing positives and negatives of RRT set out most helpfully by Ms Dolan in the balance sheet provided to the Court, I have canvassed the factors earlier in this judgment. The most important positives are that:

    i) P's life would be preserved (important to him as an individual and in accordance with his beliefs).

    ii) Withdrawal of treatment would lead to death probably within days.

    iii) P shows clear responses to his family and friends.

    iv) Treatment permits improvement of increased awareness to develop, if it can.

    The most important negatives are

    i) Some patients will die during hemodialysis.

    ii) P has a reduced life expectancy from several sources, e.g. tracheotomy, or infection.

    iii) Treatment is undignified and might be painful or cause discomfort.

    iv) Lacks any independence or dignity.

    v) P has no or an improbable potential for "meaningful" functional recovery.

44. I have reached the clear conclusion that the balance lies strongly in favour of preserving P's life through the continued provision of RRT.

    (1) On any view the treatment is not futile, it preserves his life and may do so if Dr Dewhurst is correct for perhaps some four years or more. Dr Dewhurst would have been content to provide that treatment had he been assured that that was what P wanted. It seems to me that he gains pleasure and comfort from the love and affection that he receives from his family and that is a continuing illustration not just of his conscious state but also of the importance of the continuation of such treatment.

    (2) The treatment is not overly burdensome. He does not appear to be in pain or discomfort, and the indignity of his surroundings which I put strongly in the scales is

not such having regard to his degree of consciousness that that is a strong counterbalance in the scales.

(3) The treatment is not without a prospect of success. Mr Badwan indicated that there was a possibility that his level of consciousness could improve, but in any event it preserves the quality of life that he currently has now and therefore on the evidence I regard it as worthwhile in accordance with his previous beliefs and values and expressed views.

45. There is almost nothing to rebut the very strong presumption that it is in P's best interests to stay alive. I order and direct that the renal replacement therapy should continue.

Postscript

46. The Court of Protection is cautious when considering whether to permit cessation of life sustaining treatment, where the diagnosis is unclear and particularly when the protected party is in a minimally conscious state with real or uncertain prospects of recovery that caution is all the greater having regard to the sanctity of life. The issue of differential diagnosis in this case has consumed much time. The application was launched, it might be thought, somewhat precipitously, before any SMART testing had been undertaken. The delays in the necessary and subsequent SMART testing had jeopardised the hearing and caused the hearing to be adjourned twice. These delays and uncertainties have caused increased anxiety and pressure on all concerned. These decisions are amongst the most difficult clinically and legally to take, it is of note that there was equivocation in relation to the diagnosis of VS even at an early stage, and within the treating team.

47. In W v M (Adult Patient) minimally conscious state: withdrawing treatment [2012] 1 WLR 1653 Baker J said that standardised testing is always necessary before the application is made to the Court:

> "It is 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. In future no application for an order authorising the withdrawal of ANH from a patient in a vegetative state or a minimally conscious state should be made unless a SMART assessment or similarly validated equivalent has been carried out to provide a diagnosis of the patient's disorder of consciousness and in the case of the patient thereby diagnosed as being in the minimally conscious state 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 minimally conscious state."

48. Similarly the current guidance of the Royal College of Physicians: National Clinical Guidelines on prolonged disorders of consciousness, states that diagnosis of VS or MCS should be based upon validated structured assessment tools such as SMART or WHIM. Those principles have been exposed bare by the evidence of Mr Badwan, who not only portrayed the essence of VS and MCS, but reinforced the absolute necessity for vital proper examination and consideration both in terms of neurological

assessment (he preferring a MRI scan as more instructive as opposed to a CT scan) as well as structured and holistic assessment by SMART testing at established intervals bringing together the wider evidential information in forming the ultimate conclusion as to the conscious state of the patient. Indeed that is what is after all recommended in the guidelines, and seems to me having regard to the very great difficulties faced in this case, absolutely essential. That is not to say that the clinical team were in any way not motivated by the best interests of the patient as they saw it, concerned about his state which is very very far from ideal, but in order to reach a properly informed decision and apply the legal principles without the risk of cataclysmic injustice it is quite impossible to reach a proper conclusion without it.

49. Therefore in all cases where there is any question of doubt about diagnosis, in order to eliminate mistakes or potential tragedies it is essential that those assessments are carried out in good time so that the diagnosis is clear before the Court, then the Court can conduct its own enquiry and balance.