



Neutral Citation Number: [2015] EWCOP 76 (Fam)

Case No: COP 126735597

**IN THE HIGH COURT OF JUSTICE**  
**COURT OF PROTECTION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 19/11/2015

Before :

**MR JUSTICE HAYDEN**  
**SITTING AS A JUDGE OF THE COURT OF PROTECTION**

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Between :

M	<u>Applicant</u>
- and -	
Mrs. N (By her litigation friend, the Official Solicitor)	<u>1<sup>ST</sup> Respondent</u>
Bury Clinical Commissioning Group	<u>2<sup>ND</sup> Respondent</u>
A Care Provider	<u>3<sup>RD</sup> Respondent</u>

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**Mr. P. Patel** (instructed by **Irwin Mitchell**) for the **Applicant**  
**Mr. D.Lock QC & Ms. Z Leventhal** (instructed by **Official Solicitor**) for the **1<sup>st</sup> Respondent**  
**Miss K. Gollop** (instructed by **Hempsons Solicitors**) for the **2nd Respondent**  
**Mr. V. Sachdeva QC** (instructed by **Brown Jacobson**) for the **3rd Respondent**

Hearing dates: 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup> & 6<sup>th</sup> November 2015

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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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MR JUSTICE HAYDEN

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children 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 Hayden :**

1. This is an application made pursuant to s.15 of the Mental Capacity Act 2005 (MCA) for a declaration determining whether it is in the best interests of Mrs. N to receive life sustaining treatment by means of Clinically Assisted Nutrition and Hydration (CANH) currently provided through a percutaneous endoscopic gastrostomy (PEG) tube.
2. The application is brought by M who strongly believes that the continuation of this intervention is contrary to her mother's (Mrs. N) best interests. Mrs. N lacks capacity to litigate or indeed in any aspect of decision making. Mrs. N, now 68 years old is profoundly impaired both physically and cognitively in consequence of the progressive degenerative impact of Multiple Sclerosis. It is now 23 years since Mrs. N received her diagnosis. It goes without saying that both the medical and legal landscape was profoundly different at that time. Despite the fact that N has had access to some of the most eminent practitioners in the relevant areas of medicine, that has not been able to protect her from the ravages of this condition. Multiple Sclerosis is a neurological disorder which causes myelin, the substance covering the nerves, to be destroyed. As Professor David Neary foreshadowed in his early consultations with Mrs. N the progression of the disease varies and is very difficult to predict.

**Background**

3. I have debated whether it is strictly necessary for me to review the development of Mrs. N's condition in this judgment. My instinct has been to place respect for Mrs. N's privacy and the protection of her dignity as the priority. Ultimately however, the remorseless progression of this disorder and Mrs. N's responses to each of the degenerative privations it has inflicted on her are part of the broad canvass of evidence which inform my ultimate decision. It is important that my reasoning is both transparent and uncompromised. Accordingly, I have concluded that I must, at least summarily, set out some of the key features of the medical background. It makes distressing reading. To see so many painful years reduced to a forensic chronology will be distressing to the family despite the fact that all the information is included within the court papers, much of it has been considered and analysed in court and of course the family have lived through it all.
4. Initially the physiological development of the disease was slow. However, Mrs. N found the diagnosis extremely difficult to cope with, her family consider that she became profoundly depressed, she repeatedly told her son that she would 'rather be dead'. It may be that for sometime prior to her diagnosis the disorder had begun to have its effect on her general functioning. Mrs. N's behaviour became challenging, unpredictable and increasingly difficult for her family to cope with. Between 1988 and 1990, Mrs. N's relationship with her husband deteriorated dramatically leading to separation and divorce. Mrs. N, I have been told, never entirely reconciled herself to the breakdown of her marriage. An unexpected fall in the street around the time of her divorce in 1991 led Mrs. N to consult her doctors and in due course to receive the diagnosis.
5. With the settlement from her divorce Mrs. N purchased a small bungalow for herself. As I understand the history, her daughter M, then 15 years of age, moved to live with

her father. All her family told me that Mrs. N resisted her diagnosis, she refused to use her sticks, she found the Zimmer frame provided for her to be deeply repugnant. In the home she balanced precariously between the furniture, on one occasion falling whilst alone and injuring herself significantly.

6. Gradually Mrs. N's speech became slurred, a development which irritated her profoundly. Within six years of diagnosis she became wheel chair dependant, struggled with concentration, experienced rapid mood changes and difficulties with her memory. Her power to communicate deteriorated rapidly. Her son (Z) bore the burden of the responsibility. He told me in evidence that for far too long he was resistant to his mother entering a specialist unit or care home. The situation was intolerable: Mrs. N screamed out at night disturbing and frightening her neighbours. She was discovered, on one occasion, sitting in front of the television bleeding significantly from the back of her head without any awareness of it. Z provided a regime of carers but Mrs. N would lash out at them aggressively both verbally and physically. In her prime I was told that Mrs. N could be withering and coruscating in her condemnation of people, certainly the carers felt the full sting of her articulate wrath. Perhaps unsurprisingly her friends drifted away, though her family told me that the gardener, Brian, continued to be kind and supportive and that Mrs. N thought highly of him.
7. It is difficult to be precise about dates in this account of the background history. The family were under strain, much of this is now a long time ago. I remind myself that M was very young at the time. Review of the medical records help anchor the chronology but the dates there are not always precise, being frequently dependant on a confused history. None of this really matters because the wider picture tells its own story.
8. Mrs. N and her family are Jewish. Z was able to garner help from the Jewish Federation and local social services who were patient and thoughtful in their support. Sometimes their staff were greatly challenged by Mrs. N's behaviour. By 1997 (i.e. only 6 years after the diagnosis) Mrs. N's life had changed beyond recognition. She is recorded as falling regularly at that time. Documentation relates an incident in May 1997 in which it was thought that Mrs. N had been banging herself causing significant bruising. Around this time Mrs. N developed difficulties with continence which, sadly, escalated quickly. Occupational therapists endeavoured to assist and to improve access to the home but Mrs. N was resistant to help and resentful of what she regarded as an invasion of her privacy. She loathed her wheel chair, at least initially.
9. By May 2000 the documentation suggests that the Jewish Federation were assisting with the possibility of identifying a care home. It is not entirely clear what Mrs. N's view on this option was at that stage. By June 2000 she was regularly described as being lonely. I note that in September 2000 the records reveal that Mrs. N could not walk to a chair, could not work her buzzer, would not use her Zimmer frame, cried a lot and was prone to falls. Though in my judgement the situation was barely manageable, the family, especially Z, continued to try to keep Mrs. N in her own home. They were motivated by a strong desire to preserve some semblance of independence for Mrs. N for as long as they could and, if I may say so, notwithstanding real hardship and distress to themselves.

10. In December 2002, the existing carers refused to return to the home, but new carers were employed. Mrs. N continued to fall regularly. It was often difficult for the carers to get her back into her wheelchair. There were occasional periods where matters were more manageable. Mrs. N responded well to the regular home care. She tried, albeit without much enthusiasm, according to medical records, to manage the hoist for transfers. By May 2004 Mrs. N had become doubly incontinent, she was frequently in low mood, screaming, crying and hitting staff. By October 2004 she was very weak, unable to breathe well but still extremely uncooperative. In September 2005, a period of respite was arranged, but by March 2006 it seems Mrs. N's behaviour had escalated such that she was considered to be violent to her carers. She was prescribed medication for her behavioural problems and depression. I note that the medical records reveal her to be on anti-convulsant medication to manage epilepsy. A review by a consultant in rehabilitative medicine, Dr. F. Morcos, in September 2006, identified the following, which I summarise:
- i) Severe cognitive impairment;
  - ii) Inability to communicate normally;
  - iii) Increased spasticity to limbs resulting in increased deformity and inability to sit in the wheelchair;
  - iv) Incontinence of urine and faeces;
  - v) Difficulties in swallowing, such that she was drinking fluid and mashed food;
  - vi) Significant epilepsy.
11. By September 2007 it was clear that Mrs. N was not taking in enough nutrition, even though she was by this time living permanently in a care home. Her weight was 31.9Kg with a Body Mass Index of 13Kg/m<sup>2</sup>. A swallow assessment was undertaken in October 2007. In January 2008 a PEG tube was placed, as a mechanism for supplementing normal fluid and puréed diet. The modified nutritional regime enabled Mrs. N to gain weight. Throughout 2009 Mrs. N appears to have remained at broadly the same level, though the information available is limited. By early 2010 however, it was clear that Mrs. N had deteriorated further. Fits were frequent, she had chronic sacral pressure sores and was treated regularly for chest infection. On review by Dr. F. Morcos in March 2010 Mrs. N was found to be quadriplegic, having generalised spasticity, shortening of muscles in all four limbs and to be permanently in the flexor position. Shortly before this examination MR had for the first time raised her real concern about her mother's quality of life and general condition.
12. Throughout the next few years Mrs. N continued gradually to deteriorate, her decline and increasing dementia accompanied by occasional infection and high temperature. In January 2015 M was plainly desperately distressed by the extent of her mother's condition. She saw in her no recognition of the outside world, no interaction with any stimulus and absolutely no quality of life whatsoever. The PEG, though functioning efficiently, had long outlived its anticipated life and there had been some discussion about its replacement. It was, in my judgement, the prospect of this further and inevitably intrusive procedure that led M finally to conclude that the situation for her mother was intolerable and she no longer remained alive in any sentient sense. On the

23<sup>rd</sup> April 2015 M issued the proceedings in the Court of Protection which have led to this hearing.

13. On the 14<sup>th</sup> May I made declarations that Mrs. N lacked either litigation capacity or capacity to take decisions as to her care and medical treatment. The Official Solicitor was appointed to act as litigation friend. In addition to other case management decisions I authorised the instruction of expert evidence and recorded that the issue identified by the parties was:
- i) Whether it is in Mrs. N's best interests **to continue\*** to receive the medical treatment which is presently administered to keep her alive, namely artificial nutrition and hydration by way of the PEG tube.

(\*my emphasis)

### The hearing

14. I have had the benefit of expert evidence from three very highly regarded practitioners: Professor Derek Wade, Consultant in Neurological Rehabilitation; Mr. Derar Badwan, Consultant in Rehabilitation Medicine and Dr. Krystyna Walton, Consultant in Neuro Rehabilitation. Each of them participated in the 2013 working party of the Royal College of Physicians (RCP), establishing the **National Clinical Guidelines in Prolonged Disorders of Consciousness (PDOC)**. The objectives of the group, which drew on advice from a very broad range of views and opinion, was to update and clarify the 2003 RCP report, '**The Vegetative State**'. The aim was to achieve a more consistent approach to diagnosis and management of patients with PDOC, including vegetative state (VS) and minimally conscious state (MCS).
15. The authors of the Guidance emphasise that which has become all too clear in this case and in others that I have heard, namely that consciousness is a somewhat elusive concept embracing some level of wakefulness and awareness. The Guidance defines the former as '*a state in which the eyes are open and there is a degree of motor arousal; it contrasts with sleep - a state of eye closure and motor quiescence*'. Awareness is defined as '*the ability to have and the having of, experience of any kind*'. Awareness has ultimately to be deduced from a range of behaviours '*which indicate that an individual can perceive self and surroundings, frame intentions and interact with others*'. It follows that it is not reducible to a test or clinical sign and will frequently contain a significantly subjective element.
16. The terminology in this area of medicine and law is fraught with difficulty and the potential to cause distress and offence. There is something inherently dehumanising in the term 'vegetative state'. On the other hand, that is, in part, its intention i.e. to signal the absence of sentient life, to emphasise that a patient is both unaware and free from suffering.
17. The Guidelines identify the criteria for VS. The background and origin of the term was reviewed by Sir Stephen Brown in **Airedale Trust v Bland [1993] AC 789**. It is not necessary for me to burden this judgment with that history but the relevant indicators, set out in the guidance, identifying the defining characteristics of the Vegetative State require to be stated in full:

*“The following are the essential criteria for VS. There is no evidence of:*

*1 awareness of self or environment or the ability to interact with others*

*2 sustained purposeful or voluntary behaviours, either spontaneously or in response to visual, auditory, tactile or noxious stimuli*

*3 language, comprehension or meaningful expression.*

*The following are also usually present:*

*1 cycles of eye closure and eye opening, giving the appearance of a sleep–wake cycle*

*2 spontaneous respiration and circulation*

### ***Compatible features***

*Patients may also demonstrate a range of spontaneous or reflexive behaviours including the following:*

### ***Spontaneous movements***

*The following may occur for no discernible reason:*

- chewing, teeth grinding, tongue-pumping*
- roving eye movements*
- purposeless movements of limbs and/or trunk*
- facial movements, such as smiles or grimaces*
- shedding tears*
- grunting or groaning sounds.*

### ***Reflexive movements***

*The following reflexes are usually preserved:*

- brainstem reflexes (pupillary, oculocephalic (doll’s eye), oculovestibular (caloric))*
- corneal reflex*
- reflexive oral/facial reflexes (e.g. gag, saliva swallowing, tongue thrust, bite reflex, rooting, lippursing)*
- grasp reflex.*

*Various stimuli (e.g. noxious or noise) may produce a generalised arousal response, with:*

- quickening of respiration*
- grimaces, or*
- non-localising limb movements (e.g. extension, flexor or withdrawal reflexes).*

*Eyes may turn fleetingly to:*

- follow a moving object or towards a loud sound*
- fixate a target*
- react to visual menace*

*but they do not usually follow a moving target for more than a fraction of a second.*

### ***Compatible, but atypical features of VS***

*Patients have also been described in whom isolated fragments of behaviour, such as the utterance of a single inappropriate word, occur in what otherwise appears to be a VS. These features appear to reflect the survival of ‘islands’ of cortex, which are no longer part of the coherent thalamo-cortical system required to generate awareness.*

*Features of this kind should prompt careful reassessment of the diagnosis, but they do not in themselves negate the diagnosis of VS.”*

18. The definition of MCS was first published by the Aspen Neurobehavioral Workgroup in 2002 in a paper entitled *‘The Minimally Conscious State: Definition and Diagnostic Criteria’*. It is predicated on the requirement for *‘at least one clear cut behavioural sign of consciousness indicating at least some capacity for cognitive processing’*. A diagnosis requires limited but clearly identifiable evidence of awareness of self or environment. This evidence requires to be reproducible or sustained in a number of identified behaviours (to which I shall return). The key to understanding this, as I see it, is that reproducible evidence need not be consistent.

19. The Guidance emphasises the vulnerability of such reproducible evidence to the consistency and complexity of behavioural response:

*“• Extended assessment may be required to determine whether a simple response (e.g. a finger” movement or eye blink) that is observed infrequently is occurring in response to a specific environmental event (e.g. a command to move fingers or blink eyes) or on a coincidental basis.*

*• In contrast, a few observations of a complex response (e.g. intelligible verbalisation) may be sufficient to determine the presence of awareness”.*

20. Finally and importantly, there exists a sub categorisation of MCS which again requires to be set out from the Guidance again in full:

*“MCS encompasses a broad spectrum of responsiveness from a very low level (where patients start to show evidence of non-reflexive movements) to a higher level of meaningful interaction, albeit still inconsistent.*

*Bruno and colleagues (2011) recommended a division of MCS into ‘plus’ and ‘minus’ subcategories based on the level of complexity of observed behavioural responses:*

*• MCS-plus patients show more complex behaviours such as command following.*

*• MCS-minus patients show only non-reflexive movements such as orientation to noxious stimuli, pursuit eye movements, etc.*

*However, categorisation of MCS is problematic as it could be based on a number of parameters including both the degree of consistency and the level of the behaviour. As yet there is insufficient evidence to*

*know whether sub categorisation has any prognostic significance. More research is required in this area.*

*Based on current knowledge, the GDG does not recommend formal sub categorisation at present, but emphasises the need for consistent use of standardised tools (see Section 2) to define various levels of responsiveness/interaction and longitudinal evaluation to relate presentation to outcome.”*

21. Assessment and diagnosis of these conditions requires the use of structured assessment tools. There are thirteen identified instruments but those reviewed most commonly by the Court of Protection are:
- the JFK Coma Recovery Scale – Revised (CRS-R)
  - the Wessex Head Injury Matrix (**WHIM**)
  - the Sensory Modality Assessment and Rehabilitation Technique (**SMART**)

However, it is important to emphasise that these tests have to be evaluated alongside and not in place of conventional clinical assessment and monitoring. A crucial component of this wider forensic canvass is the contribution to be made by families, friends and those who visit the patient regularly. This is set out in the Guidelines but, in my judgement, it requires bold re-emphasis in order to ensure that it is fully recognised and given appropriate weight:

*“Involvement of friends and family*

*Families and close friends play a key role in the assessment and diagnosis of patients with DOC because they are often present over prolonged periods, and because many patients respond at an earlier stage with familiar people. On the other hand, family members may sometimes interpret simple reflexive movements as more positive interactions. They need information and support from clinicians who can explain what behaviours to look for.*

*It is often helpful to ask families to use videos to record their interactions, and/or to teach them how to use tools such as the Wessex Head Injury Matrix as a structured framework to record their observations, so that these can be reviewed and interpreted by the clinical team. Similarly the SMART-INFORMS presents a structured framework for documenting and interpreting the observations of families and friends.”*

22. There are many reasons why the observations of family members and friends concerning a patient’s level of consciousness may be mistaken. Most commonly, as I have heard, this involves misinterpreting muscular spasm as something quite different and more significant. It is doubtless driven by hope and no doubt wishful thinking. That said, it is often family members who spend most time and over protracted periods with the patient. Their observations are a crucial component in the wide constellation of factors that ultimately constitute the overall assessment. Conversely,

SMART or WHIM assessments can, as here, often be undertaken at neurological rehabilitation centres by those skilled in and committed to the principles of rehabilitation and accordingly susceptible to inbuilt professional bias. Professional enthusiasm and determination are admirable qualities and are to be nurtured, but it is important to guard against overly optimistic assessment driven by a vocational desire to try to make a difference. These assessments tools have an inevitably subjective complexion to them. The use of them is however now properly regarded as essential. In **Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment) [2012] 1 WLR 1653; [2011] EWHC 2443 (Fam)** Baker J emphasised the crucial role of these assessment tools. I agree:

*“258 Secondly, this case has demonstrated the crucial role played by the formal assessment tools, SMART and 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 vegetative state. 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 a minimally conscious state. 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 vegetative state. This issue was identified by Ronald T Seel et al in the 2010 paper ‘Assessment Scales for Disorders of Consciousness: Evidence-Based Recommendations for Clinical Practice and Research’, Archives of Physical Medicine and Rehabilitation (December 2010), vol 91, cited at p 1796:*

*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 a vegetative state or a minimally conscious state 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 a 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. If an assessment scale becomes validated in the medical literature for tracking a person's recovery through the minimally conscious state, this assessment may alternatively be used in place of the WHIM.*

23. To the above, I would only add that in highlighting the 'crucial' role played by the formal assessment tools, I do not believe Baker J intended to elevate their importance to a level at which they became determinative of the outcome of cases of this kind.
24. **Re M** (supra) appears to be the only previous case where withdrawal of CANH has been considered in the context of an individual in MCS. There Baker J concluded, on the particular facts of that case, that it was not in the best interests of the patient to take the step contemplated here. The research of Leading and experienced counsel in this case, supplemented by my own research, has not revealed any other precedent.
25. With this in mind, I agree with Mr. David Lock QC and Ms. Zoe Leventhal, who act via the Official Solicitor on Mrs. N's behalf, that it is important to start the analysis of the issues in this case by reference to first principles, as set out in the **Mental Capacity Act 2005** (MCA). These are to be found within Section 1:
- “(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action”
26. As I have already indicated and as is by now evident, Mrs. N lacks capacity and requires the Court to make decisions. The framework for the decision making process is found at **Section 4** MCA which again requires to be set out extensively:
- (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 capacity in relation to the matter in question, and

- (b) if it appears likely that he will, when that is likely to be.
- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- (6) He must consider, so far as is reasonably ascertainable—
- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),**  
**(b) the beliefs and values that would be likely to influence his decision if he had capacity, and**  
**(c) the other factors that he would be likely to consider if he were able to do so.**
- (7) He must take into account, if it is practicable and appropriate to consult them, the views of—
- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,  
(b) anyone engaged in caring for the person or interested in his welfare,  
(c) any donee of a lasting power of attorney granted by the person, and  
(d) any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).
- (8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—
- (a) are exercisable under a lasting power of attorney, or  
(b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.
- (9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
- (10) “Life-sustaining treatment” means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.
- (11) “Relevant circumstances” are those—
- (a) of which the person making the determination is aware, and  
(b) which it would be reasonable to regard as relevant”

27. In relation to the application of these criteria the Official Solicitor submits:
- a) *The court is the decision maker and thus has to make the decision by:*
    - i) *considering all relevant circumstances; and*
    - ii) *Taking the steps set out in section 4(3) to (7): see section 4(2);*
  - b) *There are no limits placed on the nature or type of circumstances which may be relevant to the decision. It all depends on the facts of the case. However, in order to take a decision properly which considers all relevant circumstances, the decision maker must undertake a proper inquiry into both:*
    - i) *P's circumstances; and*
    - ii) *the type of decision that the decision maker is being called upon to make;*
  - c) *Baroness Hale explains in Aintree at §24 that the Act does not propose a totally objective best interests decision making process but a compromise which is under the label of "best interests" but nonetheless is a compromise which contains a "strong element of substituted judgment". This compromise ensures that P as a human being remains at the very centre of decision-making concerning;*
  - d) *The compromise is achieved by requiring the decision maker to "consider" (i.e. take fully into account) both P's past and present wishes and feelings: see section 4(6)(a). Whilst particular attention must be paid to expressions of P's wishes and feelings that were written down by P at a time when P had capacity, the decision maker must inquire into and then consider all other evidence of wishes and feelings before taking the decision: see §5.18 to 5.20 of the Code of Practice. That other evidence can include evidence from relatives about P's wishes and feelings which may assist the decision maker to understand P;*
  - e) *Separately to considering P's wishes and feelings, the decision maker must also consider "the beliefs and values that would be likely to influence his decision if he had capacity". This means that the decision maker must inquire into P's beliefs and values. This is not limited to religious beliefs but beliefs and values about what matters were important to P, how they affected P's view of the world and the factors which P thought were important in taking decisions for himself or herself. This part of the statutory process asks the decision maker to inquire into and reach views about the general approach that P had to making decisions for himself or herself and to ask what factors were important to P in P's own capacitous decision making as a prelude for asking what decision P would have made for himself or herself if P still had capacity;*

- f) *The court also needs to look beyond P's "beliefs and values" by considering any other factors that would, assuming P retained capacity, be have been likely to have influenced P in making the relevant decision: see section 4(6)(c)."*

To these admirably succinct submissions I would highlight the observations of Baroness Hale in **Aintree University Hospitals NHS Foundation Trust v James and others** [2013] UKSC 67; [2013] WLR (D) 421 at para 39:

*"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."*

To illustrate his submission that P remains at the very centre of the decision making process Mr Lock took me to a decision of HHJ Hazel Marshall QC in: **Re S (Protected Persons)** [2010] 1 WLR 1082 at §55 and §56. There the Judge observes as follows:

*"55 In my judgment it is the inescapable conclusion from the stress laid on these matters in the 2005 Act that the views and wishes of P in regard to decisions made on his behalf are to carry great weight. What, after all, is the point of taking great trouble to ascertain or deduce P's views, and to encourage P to be involved in the decision-making process, unless the objective is to try to achieve the outcome which P wants or prefers, even if he does not have the capacity to achieve it for himself?"*

*56 The 2005 Act does not, of course, say that P's wishes are to be paramount, nor does it lay down any express presumption in favour of implementing them if they can be ascertained. Indeed the paramount objective is that of P's "best interests". However, by giving such prominence to the above matters, the Act does, in my judgment, recognise that having his views and wishes taken into account and respected is a very significant aspect of P's best interests. Due regard should therefore be paid to this recognition when doing the weighing exercise of determining what is in P's best interests in all the relevant circumstances, including those wishes"*

28. I have given both these passages very considerable thought. I draw from them only this: where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's 'best interest's'. Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this

intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them. Finally, I would observe that an assessment of P's wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed non-verbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P's views from what he may have done in the past in circumstances which may cast light on the strength of his views on the contemplated treatment. Mr Patel, counsel acting on behalf of M, has pointed to recent case law which he submits, and I agree, has emphasised the importance of giving proper weight to P's wishes, feelings, beliefs and values see **Wye Valley NHS Trust v B [2015] EWCOP 60; Sheffield Teaching Hospital Foundation Trust v TH and TR [2014] EWCOP 4; United Lincolnshire Hospitals NHS Trust v N [2014] EWCOP 16.**

### The Code of Practice

29. Section 42 MCA requires the Lord Chancellor to prepare a Code of Practice. Every decision maker, including the court, has a statutory duty to "have regard" to the Code of Practice: see section 42(5) MCA. Paragraph 5.31 of the Code is of particular relevance. It provides:

*"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, over burdensome to the patient or whether 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 interest 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"*

30. It is clear, therefore, that the framework of the Act and the scheme of the Code of Practice place great emphasis on the importance of personal autonomy and the obligation to be alert to direct or indirect discrimination against those who lack capacity. Decisions taken in the 'best interests' of an incapacitous individual must factor in the recognition that respect for an individual's past and present (where relevant) wishes and identifiable codes and beliefs by which he has lived are a crucial part of promoting best interests. To subvert these to a substitution of an objective

evaluation i.e. to superimpose what the Court thinks best, may result in indirect discrimination. The central objective is to avoid a paternalistic approach and to ensure that the incapacitous achieve equality with the capacitous.

31. Within this legislative structure and in accordance with the philosophy that I have outlined above there exists, along with the presumption of prolongation of life, respect for the individual's right to self determination. As Munby J (as he then was) analysed in **R (Burke) v GMC & Others [2005] QB 424** the adult is arbiter of his own best interests. In this context documents setting out wishes as to medical treatment (initially described as 'living wills') were regarded as an aspect of competent adult autonomy at common law prior to the implementation of the Mental Capacity Act. Sections 24 - 26 of the Act give statutory recognition to the common law position, whilst modifying it by providing additional safeguards. They state as follows:

**24. Advance decisions to refuse treatment: general**

(1) "Advance decision" means 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.

(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.

(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.

(4) A withdrawal (including a partial withdrawal) need not be in writing.

(5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).

**26. Effect of advance decisions**

(1) If 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.

(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.

(3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.

(4) The court may make a declaration as to whether an advance decision—

(a) exists;

*(b) is valid;*

*(c) is applicable to a treatment.*

*(5) Nothing in an apparent advance decision stops a person—*

*(a) providing life-sustaining treatment, or*

*(b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.*

32. The Courts have been keen to emphasise, particularly in cases involving questions of life sustaining treatment, the importance of such advance decisions complying with the form specified by statute. The serious consequences of failure to comply have been underscored in: **W v M and S and A NHS Primary Care Trust [2012] COPLR 222 and Re D [2012] COPLR 493**. By insisting on correct procedural form the Courts have recognised that these measures strike a balance between the importance to be given to a competent adult's autonomy and concern that a person could be locked into an advance refusal that he or she would wish to change but can no longer communicate. Perhaps the most significant impact of these provisions is that they illustrate that the presumption of life, predicated on what is often referred to as the 'sanctity of life' or the 'intrinsic value of life', can be rebutted (pursuant to statute) on the basis of a competent adult's cogently expressed wish. It follows, to my mind, by parity of analysis, that the importance of the wishes and feelings of an incapacitated adult, communicated to the court via family or friends but with similar cogency and authenticity, are to be afforded no less significance than those of the capacitous.

### **Mrs. N's present condition**

33. There is complete agreement between the doctors that Mrs. N is suffering from very advanced Multiple Sclerosis. Given that this is a degenerative disorder the concept of rehabilitation has strikingly limited utility. Whilst some pragmatic adjustments could be made to improve the very limited quality of Mrs. N's life, when these were analysed properly, all agreed they could accurately be characterised as palliative care. In so far as life expectancy can effectively be predicted the consensus appears to be that it could be in the region of three to five years.
34. The primary area of controversy between the doctors has been on the question of Mrs. N's level of consciousness. Mr. Badwan and Dr. Walton have misgivings about the applicability of the term MCS for an individual at the end stages of any progressive disorder who has impaired levels of arousal and interaction. The practical use of the term 'MCS' has been, Dr. Walton tells me, connected with sudden onset severe brain injury from whatever cause. In the context of brain injury the clinical objective is to evaluate consciousness as a foundation for rehabilitation. As it is agreed that this is 'not the case for people with progressive neurological conditions such as multiple sclerosis' the terminology appears to them to be an uncomfortable fit.
35. However, they considered that the SMART assessment contributed to an understanding of Mrs. N's level of awareness and both agreed, in evidence, that it had to be considered alongside the broader canvass of available material, particularly

experienced clinical observations. By way of completeness I should clarify that all three doctors accepted that there were no other tests of awareness that were likely to be helpful and each recognised that the Guidance specifically contemplated PDOC in both the final stages of dementia and other ‘progressive neurodegenerative disorders’. In other words, categorisation was not confined to cases of sudden onset profound acquired brain injury.

36. Though I heard evidence from Professor Wade, Mr. Badwan and Dr. Walton individually in the witness box, I also encouraged discussion between the three whilst each gave their evidence (a hybrid version of a practice known as ‘hot tubbing’). Though there are differences between them, much of which focuses on nomenclature, I was impressed by their respect for each others’ views and their willingness continually to re-evaluate the available evidence. Ultimately there was agreement that the modalities in the SMART assessment really only established, with any kind of forensic reliability, that Mrs. N could ‘fix’ and ‘track’ objects within her line of vision. That is to say the test was reproduced with reliability, though not with consistency.
37. This agreement is highly significant. On a strict interpretation of the National Clinical Guidelines such a finding would appear to exclude a diagnosis of Vegetative State. Mr. Badwan and Dr. Walton both considered that the priority of achieving consistent diagnosis in this field prevented their identifying any case as VS where there was found to be visual fixing and tracking. For them, this feature in and of itself was sufficient to preclude such a diagnosis.
38. Professor Wade took a different view. VS and MCS were terms devised to be applied to patients with prolonged disorders of consciousness, irrespective of aetiology. In simple terms there was no reason to regard differently a patient with VS or MCS according to whether their condition arose in consequence of progressive neurological disorder or acute event. Professor Wade considered that Mrs. N’s current clinical condition is such that there is no evidence at all to suggest that she has any awareness of either her own situation or her own environment. She is, he said, ‘incapable of undertaking any voluntary or willed goal-directed actions’. There is no evidence that Mrs. N experiences pleasure, pain or distress says Professor Wade. In court Mr. Badwan accepted that whilst there was physiological evidence of response to pain he couldn’t determine whether that had ‘any implications on her feelings’. He also agreed that such is the degeneration of Mrs. N’s brain that even the capacity for pain of a physiological nature could only be very limited. Dr. Walton confirmed her agreement on these points.
39. Professor Wade considered that Mrs. N was in fact in a vegetative state. Given that this seemed to be out of step with the Guidelines, to which he had contributed, Mr. Badwan and Dr. Walton plainly but again respectfully considered this to be rather surprising. Professor Wade agreed that Mrs. N has an intact visual pathway. He agreed that she periodically tracks people moving within her visual field for periods of up to ten seconds at a time. However, he emphasised that there did not appear to have been response to specific stimuli or discrimination between people. On this I agree with Professor Wade nor do I consider that Mr. Badwan or Dr. Walton disagree.
40. Professor Wade, in his report of the 25<sup>th</sup> October 2015 and in his evidence, drew my attention to a number of studies to support his proposition that contrary to the

Guidelines there is evidence of visual fixation and tracking in patients in VS. He pointed out that visual tracking (as opposed to fixing) has been regarded as a factor **predicting** (his emphasis) recovery into MCS. However, in a study undertaken by **Giacino JT, Kalmar K [1997] (*The Vegetative States: a comparison of clinical features and functional outcome*)** Professor Wade emphasises three of the eleven patients did not, in fact, recover into MCS. Accordingly, as I follow the theory, tracking must logically be present in some VS cases.

41. Professor Wade placed greater emphasis on another study in which patients with tracking were found to have clinical features of a vegetative state and, in addition, similar alterations in cerebral metabolism to other patients in VS. (**Bruno MA, Vanhauzenhuysse A, Schnakers C, Bolym, Gosseries O, Demertzi A, Mageruss, Mooneng, Hustinxr, Laureys S [2010] *Visual fixation in the vegetative state: an observational case series PET study***). Accordingly, there could be no logical nexus, Professor Wade concluded, between visual tracking and awareness. He reminded his colleagues that notwithstanding the way in which the Guidelines had been crafted, the working party were very much aware of the research of **Laureys S, Owen AM, Schiff ND, (2004): *Brain function in coma, vegetative state and related disorders***. In his report prepared for these proceedings, he quoted the following extract from that research:

*“The diagnosis of vegetative state should be questioned when there is any degree of sustained visual pursuit, consistent and reproducible visual fixation, or response to threatening gestures, but these responses are observed in some patients who remain in vegetative state for years”.*

42. Ultimately, Professor Wade considered that the Guidelines generally, but this feature in particular (i.e. visual fixing and tracking), should not be regarded as a strait jacket to diagnosis nor to oust the proper application of the differential diagnostic method (i.e. consideration of the full symptomatology). This was to go too far for Mr. Badwan and Dr. Walton. They considered that it threatened uniformity of approach to these cases nationally and in an area of medicine where the need for consistency weighs particularly heavily. The Guidance (2013) can hardly be said to be dated they argued.
43. I find both approaches here to be so coherently reasoned that I am unable to prefer one to the other. Fortunately, I do not consider that I need to make a choice because the reality of the disagreement is far narrower clinically than is the theoretical divide. Mr. Badwan and Dr. Walton ultimately accept that whilst the assessment modalities may have their limitations in the context of neurological degeneration, they are all that is currently available and do cast some light on Mrs. N’s level of awareness. They agreed that notwithstanding their reservations about the correct terminology here that if they were evaluating a patient with sudden onset brain injury they would both consider her to be at a low level of MCS (i.e. the most severe). Professor Wade accepted the complications of assessing Mrs. N’s awareness, particularly in consequence of her severe motor impairment. He observed:

*“I think that the primary observation that I would make in relation to formal assessments is that they should be considered as a structured way to make observation of behaviour where, the important aspect is*

*to record the actual behaviour seen so that it can be interpreted in the clinical context. Interpretation is as important as observation.”*

44. What emerges therefore is agreement between the doctors as to the clinical findings and disagreement as to the correct nomenclature to be applied. Whether Mrs. N is in VS or MCS has important consequences for how I apply the law but it is an arid debate clinically given all now agree on the relevant medical facts.
45. It is well established that if I conclude Mrs. N to be in MCS any evaluation of her best interests must involve a proper identification of the advantages and disadvantages of each proposed course. This approach is conveniently referred to as the ‘balance sheet’, a test articulated, in this context, by Thorpe LJ in **Re A (Male Sterilisation) [2000] 1 FLR 549**. At paragraph 560 Thorpe LJ observed:

*“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”.*

46. It is, of course, important to recognise that in this process some factors will have far greater weight than others. The balancing exercise is qualitative rather than merely numerical. The point is made in the deft analogy of McFarlane LJ in: **Re F (A Child) (International Relocation Cases) [2015] EWCA Civ 882 at para 52:**

*Finally I wish to add one further observation relating to paragraph 29 of Ryder LJ's judgment where my Lord suggests that it may be helpful for judges facing the task of analysing competing welfare issues to gain assistance by the use of a 'balance sheet'. Whilst I entirely agree that some form of balance sheet may be of assistance to judges, its use should be no more than an aide memoire of the key factors and how they match up against each other. If a balance sheet is used it should be a route to judgment and not a substitution for the judgment itself. A key step in any welfare evaluation is the attribution of weight, or lack of it, to each of the relevant considerations; one danger that may arise from setting out all the relevant factors in tabular format, is that the attribution of weight may be lost, with all elements of the table having equal value as in a map without contours.*

47. By contrast, if I conclude that Mrs. N had no awareness at all, i.e. that she was in VS, the ‘balance sheet’ analysis does not apply, the diagnosis itself establishing the futility of further intervention. Definitive authority for this proposition is found in the judgment of Sir Mark Potter, in: **A Hospital v SW [2007] Med LR 273 at [28]**:

*“Whereas in most cases relating to the propriety or desirability of treatment for mentally incapacitated patients, it is requisite to draw up a balance sheet of the benefits and dis-benefits of providing medical treatment...it was made clear in the Airedale case that there is effectively no balancing operation to be performed where a person has a definite diagnosis of PVS, the futility of the treatment justifying its termination”.*

48. It is not the role of the Judge in the Court of Protection to arbitrate on issues of medical controversy see **A Local Authority (1) K (2) N (3) N (By his children’s guardian MK) [2011] EWHC 1156 (Fam); [2011] 2 FLR 165**:

*“59. It remains my view, however, that it is not the function of the Judge to become involved in medical controversy except in a very rare case where such a controversy is itself an issue in a case and a judicial assessment of it becomes necessary for the proper resolution of the proceedings.”*

49. Were I to agree with Professor Wade that VS is the correct diagnosis here it would require me to endorse an opinion which steps outside the recently drafted and widely respected guidelines. Whilst I do not criticise Professor Wade for doing so, particularly as he supports his opinion with well respected and peer reviewed research, I am not prepared to follow him. The research was known to the working party drafting the guidelines. The opinion articulated here by Professor Wade was a perspective clearly contemplated by the committee. The view was however not incorporated into the guidance, I believe because the research base was as Dr. Walton suggested really rather limited. Moreover, even cognitive functioning to this very limited degree seems to be inconsistent with the general premise of a vegetative state. I am bound to say, that for my part, where some level of awareness remains, however limited it may be, I instinctively consider that in such cases (whatever the label given to the condition) a decision to withdraw treatment should only be made after a full analysis of P’s best interests. If I had accepted Professor Wade’s conclusion it would have followed, inevitably, that no such analysis was required. It is, as I have stated, axiomatic that if P is in a vegetative state, treatment is futile.

### **The views and attitudes of Mrs. N**

50. I heard evidence from Mrs. N’s daughter, son and ex-husband. What was most striking about their respective accounts was their complete candour. None of them made even the slightest attempt to bend the evidence to their preferred outcome. Where evidence was ambivalent, in the sense that it carried a potential interpretation which pointed away from the course that they considered to be in Mrs. N’s best interest’s, they offered it to me to consider without embellishment or distortion. Though each of them had very different relationships with Mrs. N and loved her, in

different ways, none was prepared to overlook her faults, foibles and weaknesses of personality. Mrs. N emerged as woman who could at times be capricious, selfish and seemingly shallow. Her prevailing characteristics though came through most loudly from the evidence. She was immensely 'proud', jealous of her privacy, extraordinarily 'feisty' (the word most frequently used by the family) and profoundly loyal to her children.

51. At 18 years old Mrs. N found herself in a very difficult situation. Following what was a superficial relationship with a man 10 years her senior she became pregnant. In 1960s Britain that situation still carried a social stigma, particularly in the close knit Jewish community where she grew up. Mrs. N's parents were a tower of strength to her. They gave her unfaltering support and offered Z, their grandson, the same unconditional love that they had always shown their daughter. With the benefit of this emotionally secure foundation for herself and her baby, Mrs. N took a course which, particularly by the standards of the day, required enormous courage and resolve. Z's father refused to acknowledge his paternity and so Mrs. N pursued the paternity claim through the courts. This action, which I have been told was resisted at every stage, was regarded by Mrs. N as nothing less than Z's own basic right to have his paternity known and recognised. She was entirely unprepared to compromise on anything less than what she perceived to be Z's full legal recognition and entitlement to proper financial provision.
52. It is important to remember that this claim was pursued at a time when DNA testing was not available. The court, in those days, required evidence which was intimate, often rather graphic and inevitably embarrassing for a young woman from a protected background. Mrs. N succeeded in her claim. Paternity was established, maintenance ordered but Z and his father have never met. What is striking is how each of the family members I heard from wanted to tell me about this aspect of their history. They plainly respect Mrs. N for her courage and determination and each recognises the personal cost and effort involved. They all knew her as a woman for whom outward or public appearance was enormously important. I think each of them struggled to imagine how she had managed to force herself through litigation of that kind. They recognised in it an indomitable spirit which they saw flashes of in different contexts over the years.
53. Mrs. N, all agreed, 'lived to shop'. She loved clothes, she was extremely attentive to her appearance. M told me that her mother never left the house without 'her hair and nails being immaculate'. She would regularly meet her friends for lunch at fashionable restaurants. She 'loved the good life'. Following her marriage to L in 1976, Mrs. N's life was very comfortable. The family lived in a smart well appointed home in a fashionable area and were able to take regular foreign holidays. In his evidence L told me, without sentimentality, that he had grown up in the east end of London in a kind of poverty that simply would not be recognised in the UK today. He had built a successful business in what he referred to as the 'garment and fashion' industry (I suspect he might well have used a less formal description outside the courtroom). He told me that he was simply unable to spend or enjoy the money he was able to make. His background had simply disabled him from this ability. This was not said in a mean spirited or lugubrious manner, it simply showed a capacity for self reflection. Mrs. N had no such difficulty, he told me and I realised from L's evidence that he was able to take vicarious pleasure in his wife's enjoyment of the

income he provided. That said I am equally sure that there were occasions where Mrs. N rather tested him with her occasional profligacy.

54. Mrs. N was devoted to her parents. When she moved away with her husband, in the early days of the marriage, she found the separation difficult to endure and the couple soon relocated to reunite Mrs. N with her parents. Z too was close to his grandparents, in some ways seeing them as his own parents. The grandparents were strong and independently minded, providing much support for their daughter and her family. Sadly, they both fell victim to senile dementia in their early eighties.
55. Mrs. N's reaction to this shocked her husband and both her children. Though she had loved her parents dearly she was resistant to visiting them when they moved to live in a care home. She hated seeing them in such a diminished state (as they undoubtedly were to her eyes). L and the children visited regularly but even under pressure Mrs. N would only go rarely. Mrs. N recalls her mother saying, at the time, "if I ever get like that shoot me!". That is an expression that most of us have heard and quickly discounted. M was still a young girl, and had not heard it used before. It shocked her and has remained with her. It may be that something of the sheer honesty of the remark communicated itself to her. This statement however, coupled with her mother's resistance to visiting her parents and her obvious distaste for their mental decline, left a powerful impression on M.
56. Mr Lock emphasises that L shared the same recollection and also regarded it as a serious observation, particularly when viewed alongside his wife's reaction to her parents. Moreover, it is entirely consistent with her expressed wish, to him, that she did not want to be a burden. In the context of intimate conversations between a couple who had been married for 15 years this is important evidence. L shared Mrs N's views and told her so. He has now had solicitors draw up for him an 'advanced decision to refuse treatment', reflecting his identical perspective.
57. The family do not consider that Mrs. N's response to her parents dementia was either thoughtless or unkind. They regard her as heartbroken, she simply could not bear to see what they had become. She was, they communicated to me, determined to remember them as they had been. This behaviour, say the family, casts a very bright light on what Mrs. N would want for herself in her present predicament. Few, they contend, were less well placed to withstand the ravages and vicissitudes of this degenerative disease than Mrs. N. Each family member has, in their different way, emphasised to me that Mrs. N's total denial of her condition, her refusal to use her stick, the Zimmer frame, the emergency buzzer and her resistance to letting carers into a home life that had once been immaculate, was not an indication of a determination to overcome the disease but a deep resistance to acknowledging its existence at all. It was too painful for Mrs. N even to contemplate. When the reality of her circumstances did bubble to the surface she railed in intemperate language to her son that she wanted to die. This was now nearly twenty years ago.
58. I have been told that Mrs. N kept the family home immaculately clean; she was as obsessive about its appearance as she was regarding her own presentation. As well as candour the family have displayed great humour. Much as Mrs. N enjoyed fine dining and stylish restaurants, they told me, she brought no tips or ideas back to her own pristine kitchen. Without a moment's hesitation and with one voice the entire family told me, on my enquiry, Mrs. N was a dreadful cook! Appearance mattered a

great deal to Mrs. N; it may be that this was, in part, the legacy of her teenage pregnancy. Respectability, security and a good face to the world achieved very high importance to her. It would be too easy to criticise these preoccupations as shallow; it would require discounting her feistiness, her pride and her commitment to her children.

59. In my account of Mrs. N's views and attitudes to life I have focused on the family's evidence because this is what they feel brings her personality into the courtroom. It is not always easy to see why it is that they select particular stories. For example, I am not sure why they have placed so much emphasis on Mrs. N's paternity action. Certainly it reveals her feistiness but it does not translate easily into information which casts light on what she would, in her present circumstances, now wish for herself. I have wondered whether the family wish me to infer that she is a strong enough personality to take control of how she lives out the remaining period of her life. I have wondered whether they have highlighted this episode in her life as a counter balance to some of her more superficial pre-occupations. Ultimately, I have regarded it as part of a picture which helps me to understand Mrs. N's moral imperatives and the code by which she lived her life. The family has each, in their different ways, been able to create a clear and compelling impression of who Mrs. N is and what her values were. They have, if I may say so, given her a clear voice in this courtroom.
60. I am left with little doubt that Mrs. N would have been appalled to contemplate the early pain, increasing dependency and remorseless degeneration that has now characterised her life for so long. I have no difficulty in accepting the family's view that she would not wish to continue as she is. More than that, she would have wished to have discontinued her treatment some considerable time ago.
61. For one who has set such store by outward appearance and who has been so attentive to the impression she created on others, her decline, in the way I have outlined, is particularly poignant. Some might well have endured all that Mrs. N has with phlegmatism and fortitude. Mrs. N is simply not such a person. I am satisfied, as the family say, that some considerable time ago now she had simply had enough and that, as they see it, to force nutrition and hydration upon her is to fail to respect the person she is and the code by which she has lived her life.

### **The Official Solicitor's change of position**

62. At the outset of this case and until the conclusion of the family's evidence the Official Solicitor took the view that the strong presumption in favour of the benefit of the continuance of life had not been displaced. It was emphasised that as disabilities developed, so the perspective of the disabled person might change. Views expressed prior to the onset of Multiple Sclerosis have value, it was submitted, but equally the limitations of such statements must be recognised. It was stressed that there was no direct evidence as to what Mrs. N wanted for herself as her medical condition progressed. In uncompromising but entirely proper terms the Official Solicitor stated that the comparison to be made was not how Mrs. N presented before her current suffering but was in truth 'a comparison between her present life and no life at all'.
63. However, following the family's evidence, Mr Lock and the Official Solicitor himself had a lengthy consultation at the end of the court day. I noticed that the Official

Solicitor himself was present in court for part of M's evidence. The following morning I was told that having been fully advised of the family's thoughtful perspectives as to Mrs. N's likely wishes, the Official Solicitor had concluded that it would be wrong for him to continue to oppose the application. The sincerity of the family's evidence, their obvious capacity for self reflection and their candid and non-judgmental accounts of their mother's life and beliefs created a very powerful impression and I was not wholly surprised to learn that the Official Solicitor had changed his position.

64. All this said, the Court was then left in the position of contemplating a serious and important development in the evolution of the case law in the absence of opposing arguments. I was instinctively uncomfortable with that situation. Accordingly, as is by now clear from this judgment, I required each of the experts to give evidence as well as those conducting the SMART assessment. Mr Lock, notwithstanding the change of position, continued to act, in effect, as amicus to the Court, testing the evidence as it evolved.

### The case law

65. The Parties have referred me to all the relevant case law, the foundation for which is the powerful judgments in **Airedale NHS Trust v Bland [1993] AC 789**. It is impossible for any judge contemplating an application of this kind not to be halted by the uncompromising logical integrity of the judgment of Hoffman LJ (as he then was). At page 825 F the key question is framed in stark terms:

*“Can it ever be right to cause the death of a human being by deliberately depriving him of food? This is not an area where only difference can be allowed to exist between what is legal and what is morally right. The decision of the court should be able to carry conviction with the ordinary person as being based not merely on legal precedent but also upon acceptable ethical values”*

66. I have also found the sensitive observations of Baker J in: **Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment) [2012] 1WLR 1653** to be particularly thought provoking:

*“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 diminished. 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.”*

67. Posing the question in the way that Hoffman LJ did might lead the reader to conclude that there could only be a negative answer to the question ‘can it ever be right to cause the death of a human being by deliberately depriving him of food?’ In fact the answer that emerges later in the Judgment is ‘yes’, it can be right. At para 826 E:

*“Our belief in the sanctity of life explains why we think it is almost always wrong to cause the death of another human being, even one who is terminally ill or so disabled that we think that if we were in his position we would rather be dead. Still less do we tolerate laws such as existed in Nazi Germany, by which handicapped people or inferior races could be put to death because someone else thought that their lives were useless.*

*But the sanctity of life is only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular for his right to choose how he should live his own life. We call this individual autonomy or the right of self-determination. And another principle, closely connected, is respect for the dignity of the individual human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person.*

*No one, I think, would quarrel with these deeply rooted ethical principles. But what is not always realised, and what is critical in this case, is that they are not always compatible with each other. Take, for example, the sanctity of life and the right of self-determination. We all believe in them and yet we cannot always have them both. The patient who refuses medical treatment which is necessary to save his life is exercising his right to self-determination. But allowing him, in effect, to choose to die, is something which many people will believe offends the principle of the sanctity of life. Suicide is no longer a crime, but its decriminalisation was a recognition that the principle of self-determination should in that case prevail over the sanctity of life”.*

Later at page 829 H:

*Thus it seems to me that we are faced with conflicting ethical principles. On the one hand, Anthony Bland is alive and the principle of “the sanctity of life says that we should not deliberately allow him to die. On the other hand, Anthony Bland is an individual human being and the principle of self-determination says he should be allowed to choose for himself and that, if he is unable to express his choice, we should try our honest best to do what we think he would have chosen. We cannot disclaim this choice because to go on is as much a choice as to stop. Normally we would unquestioningly assume that anyone would wish to live rather than die. But in the extraordinary case of Anthony Bland, we think it more likely that he would choose to put an end to the humiliation of his being and the distress of his family. Finally, Anthony Bland is a person to whom*

*respect is owed and we think that it would show greater respect to allow him to die and be mourned by his family than to keep him grotesquely alive.*

Finally I would emphasise at page 830 G:

*“In my view the choice which the law makes must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it has become almost empty of any real content and when it involves the sacrifice of other important values such as human dignity and freedom of choice.”*

68. Baroness Hale in **Aintree University Hospital Trust v James [2014] AC 591**: also took care to ensure that the question was properly formulated not as the ‘withholding of treatment’ but focused instead on the patient’s best interest. At para 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.”*

69. I have throughout this judgment referred to hydration and nutrition as ‘treatment’. All agree that it should be regarded as such. Lord Goff clarified the point in **Airedale (HL)** p870 at A:

*“There is overwhelming evidence that, in A 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.”*

## Conclusions

70. As is clear from the above analysis this case is not concerned with a right to die. No such right exists. What is in focus here is Mrs. N’s right to live her life at the end of her days in the way that she would have wished. I am required to evaluate the ‘inviolability of life’ as an ethical concept and to weigh that against an individual’s

right to self determination or personal autonomy. Not only do these principles conflict, they are of a fundamentally different complexion. The former is an ideological imperative found in most civilised societies and in all major religions, the latter requires an intense scrutiny of an individual's circumstances, views and attitudes. The exercise is almost a balance of opposites: the philosophical as against the personal. For this reason, as I have already indicated, I consider that a formulaic 'balance sheet' approach to Mrs. N's best interests is artificial.

71. As I have already set out and at some length, I am entirely satisfied that Mrs. N's views find real and authoritative expression through her family in this courtroom. I start with the assumption that an instinct for life beats strongly in all human beings. However, I am entirely satisfied that Mrs. N would have found her circumstances to be profoundly humiliating and that **she** would have been acutely alert to the distress caused to her family, which **she** would very much have wanted to avoid. LR told me that Mrs. N would not have wanted to have been a burden; that I also believe to be entirely reliable.
72. There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain. There will undoubtedly be people who for religious or cultural reasons or merely because it accords with the behavioural code by which they have lived their life prefer to, or think it morally right to, hold fast to life no matter how poor its quality or vestigial its nature. Their choice must be respected. But choice where rational, informed and un-coerced is the essence of autonomy. It follows that those who would not wish to live in this way must have their views respected too.
73. I have declined here, contrary to Professor Wade's opinion, to conclude that Mrs. N meets the criteria for vegetative state. However, I would wish to emphasise that, on the facts of this particular case and for the reasons that I have already explained, any 'bright line' delineation between VS and MCS is largely, perhaps even entirely, artificial.
74. All the experts agree that if nutrition and hydration is withdrawn pursuant to a structured palliative plan Mrs. N will not feel any pain. Indeed it seems unlikely that she has the capacity to experience pain at all. It is also common ground that Mrs. N has no opportunity to achieve any kind of rehabilitation or recovery however limited. Her particular condition is remorselessly progressive. I am entirely satisfied that there is no prospect of her achieving a life that **she** would consider to be meaningful, worthwhile or dignified.
75. Mrs. N can fix her vision and follow a moving object on a regular though not consistent basis. She has little if any recognition of what the object might be. This is the sole extent of her awareness and it appears that she has been in this condition since approximately 2008 (i.e. 7 years). Ultimately, I have concluded that her wishes, so thoughtfully presented by her family, coupled with the intrusive nature of the treatment and its minimal potential to achieve any medical objective, rebut any presumption of continuing to promote life. Quite simply, I have come to the conclusion that it would be disrespectful to Mrs. N to preserve her further in a manner I think **she** would regard as grotesque.

76. I should record that both the second and third respondents have taken a neutral stance to this application, a course which I regard as entirely proper. Mr Sachdeva QC, who appears for the third respondents, draws my attention to the significance of Article 8 ECHR which provides:

***“Right to respect for private and family life***

*1. Everyone has the right to respect for his private and family life, his home and his correspondence.*

*2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.”*

77. In **R (Purdy) v DPP [2009] UKHL 45; [2010] 1 AC 345** Baroness Hale observed:

*“66 ... If we are serious about protecting autonomy we have to accept that autonomous individuals have different views about what makes their lives worth living. There are many, many people who can live with terminal illness; there are many, many people who can live with a permanent disability at least as grave as that which afflicted Daniel James; but those same people might find it impossible to live with the loss of a much-loved partner or child, or with permanent disgrace, or even with financial ruin.”*

78. The well known passage in **Pretty v United Kingdom [2002] 35 EHRR 1** was also cited with approval and requires to be restated here. It articulates in simple terms the dilemma the courts and society more generally face in cases of this kind:

*“65 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.”*

79. I consider that in this case respect for Mrs. N’s dignity and human freedom overwhelms further prolongation of life and therefore I am prepared to grant the declaration in the terms annexed to this judgment.

