Neutral Citation Number: [2018] EWCOP 41

Case No: 1334554T

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 21/12/2018

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

- -

Between :

NHS Cumbria CCG	**Applicant**
- and -	
Mrs Jillian Rushton	**1st Respondent**
By her litigation friend, the Official Solicitor	
- and -	
Mr Tim Rushton	**2nd Respondent**

- -
- -

Ms Bridget Dolan QC (instructed by Ward Hadaway, Newcastle) for the Applicant
Ms Fiona Paterson (instructed by the Official Solicitor) for the 1st Respondent

Hearing dates: 21 December 2018

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered in open court.

The Honourable Mr Justice Hayden :

1. This is an application regarding the proposed withdrawal of clinically assisted nutrition and hydration in respect of Mrs Jillian Rushton, who is now 85 years of age. Since sustaining a traumatic head injury in December 2015, Mrs Rushton has suffered from a prolonged period of disorder of consciousness. Insofar as a label is relevant, the consensus of medical opinion, in respect of which there is no dissent at all, is that she is in a persistent vegetative state (PVS). In their recent guidance, **'Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent'**, the Royal College of Physicians and the British Medical Association have noted that the importance of obtaining a precise and definitive diagnosis has reduced. It is recognised by the Courts and clinicians that drawing a firm distinction between vegetative state and minimally conscious state is frequently both artificial and unnecessary. In practice, when assessing best interests, information about the patient's current condition and prognosis for functional recovery and the level of confidence with which these can be evaluated is invariably of greater importance than a precise diagnosis.

2. Mrs Jillian Rushton was formerly a nurse. I have heard that she was fortunate enough to have had an extremely happy and long marriage. I have noticed as I have listened to her family that is it almost impossible for them to mention her, even now 14 years after the death of her husband, without mentioning him too, almost in the same sentence.

3. Dr Donald Rushton, a former pathologist died from prostate cancer. I have heard from his son that when he received his diagnosis, he and his wife discussed how they would spend their remaining days together. They determined that the emphasis should be on the quality of his life rather than on its duration. Dr Rushton declined chemotherapy with little, if any, hesitation. He described it to his family as like putting *"Vim in his veins"*. He was very clear that the pain and discomfort of the process did not justify any prolongation of life.

4. That was a brave decision, but its significance to my mind is that it was a joint one. Having heard evidence on these issues in other cases, I have noted that those suffering from terminal illnesses sometimes feel the need to undertake chemotherapy for their partners and families. This couple plainly had frank and open discussions, rooted in a life time of being able to speak openly and honestly with each other. They came to their decision jointly and neither ever regretted it. It must have been a very difficult decision for Mrs Rushton to take; it also says a great deal about her attitude towards and her acceptance of death.

5. By all accounts, Mrs Rushton was something of a 'star' in her youth; certainly, Dr Rushton thought so. Indeed, he continued to think so long after her youth had gone. I was told how on one occasion he remarked to his grandchild that his grandmother was the most attractive girl he had ever seen. There is, I am told, a photograph (in this family) of Dr and Mrs Rushton going out to dinner, he smart in black tie and she elegant in a polka dot dress, looking in the family's eyes like the actress, Audrey Hepburn.

6. Mrs Rushton was full of life. She enjoyed bird watching, she enjoyed classical music, she was a member of a sewing group and joined in many activities that were

associated with her local community and church. She strikes me as one of life's organisers. Indeed, I am told that she managed the catering at one of her children's weddings, for 120 guests.

7. When her husband died she struggled on as best she could, keeping as busy as possible. Although there were times, at family gatherings surrounded by her sons and grandchildren, when the sunshine came back into her life, the reality appears to have been as her son, Hugh, told me so eloquently, that after her husband's death, "*the sweetness went out of her life*."

8. Her health began to decline and in August 2014 she was admitted to hospital with pneumonia. She had, by all accounts, enjoyed good health hitherto but after that episode her strength began to fail her and her overall well-being deteriorated.

9. Her son, Tim Rushton, gradually assumed the role of her carer. It must be said that he is devoted to her. He was, he tells me, *"the baby of the four brothers"*. I suspect, from what I have heard, that Mrs Rushton gave to him care and love of a slightly different kind to that of the older brothers. They are all fit, healthy, competent in life, but they see, as do I, a certain vulnerability in Tim. His brother Hugh, who I can see he respects very much, describes him as "*obsessive compulsive*" and certainly I have noticed that there is something rather concrete in his thinking. Though he could not do enough for his mother and has been solicitous to her every need, he is plainly burdened with a sense of his own inadequacy, perceiving himself (entirely wrongly) as not having done enough for her or of not having cared sufficiently.

10. When Mrs Rushton was discharged from hospital she was conspicuously frail and it became obvious to her sons that there was, in addition to a physical frailty, a gradual decline in her general cognitive functioning. She was, I am told, frequently agitated, often weepy and distressed. Her personality was different and she became uncharacteristically quick to anger. She had some insight into her own deterioration; the papers are littered with references to her communicating that she "*did not want to wake up in the mornings"* and how much she missed her husband, Donald.

11. It emerged that she was in fact suffering from a cognitive impairment which resulted in due course in a diagnosis of cerebral vascular disease. One of its effects on her was to upset her balance; she experienced frequent falls which plainly undermined her confidence and left her feeling vulnerable.

12. On the 21 December 2015, Mrs Rushton fell and suffered a major trauma to her head. It was so significant that she was not expected to survive and as Ms Dolan QC, who today appears on behalf of NHS Cumbria CCG, has told me, she was placed on a palliative care plan. However, Mrs Rushton had a good physical constitution and, of course, the doctors are not always right. On that admission in 2015, a naso - gastric tube was inserted to feed her. It was done instinctively by conscientious medical staff, whose every instinct would have been to promote her welfare. When her condition improved the NG tube was replaced by a percutaneous endoscopic gastrostomy (PEG) which was inserted at the end of January 2016, in part in order to facilitate her care back at home with her son.

13. An important feature in the background of this case requires to be highlighted. It has been the subject of scrutiny and anxious thought. On 24th July 2014, approximately a year before she sustained her brain injury, Mrs Rushton signed an Advance Decision, in which she indicated her refusal of treatment in certain circumstances (see below). The Mental Capacity Act 2005 gives statutory recognition to and governs the applicability of advance decisions to refuse what are referred to as "*specified medical treatments*." Within these provisions, which build upon the common law, there are set out a number of conditions which require to be met in order for the decision to be valid and applicable. It is useful to set these out here:

> ***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).*
>
> ***25 Validity and applicability of advance decisions***
>
> *(1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time–*
> *(a) valid, and*
> *(b) applicable to the treatment.*
> *(2) An advance decision is not valid if P–*
> *(a) has withdrawn the decision at a time when he had capacity to do so,*
> *(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or*
> *(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.*
> *(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.*

(4) An advance decision is not applicable to the treatment in question if–
(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.
(5) An advance decision is not applicable to life-sustaining treatment unless–
(a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
(b) the decision and statement comply with subsection
(6) A decision or statement complies with this subsection only if–
(a) it is in writing,
(b) it is signed by P or by another person in P's presence and by P's direction,
(c) the signature is made or acknowledged by P in the presence of a witness, and
(d) the witness signs it, or acknowledges his signature, in P's presence.
(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

14. The force of the advanced decision is given effect by s.26 MCA 2005 in these terms:

(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.

Mrs Rushton's document is an important one and must be approached with care, recognising the importance of the statutory safeguards. It is inevitable that, even with some medical knowledge, Mrs Rushton could not have foreseen all medical eventualities or have anticipated with accuracy the circumstances in which she ultimately found herself.

15. At chapter 9 of the Code of Practice, there is set out important guidance and non-exhaustive criteria intended to illuminate best practice. These have already been subject to judicial endorsement in, for example, the case of ***X Primary Care Trust v XB EWHC [2012] 1390 Fam***. In particular, chapter 9, whilst emphasising there is no set form, indicates that it is helpful to include specific information. Firstly, and obviously, the full details of the maker of the document need to be included. Secondly, and this in my view is of paramount importance, the name and address of the general practitioner should be identified and further, it should be specified whether they are to be sent a copy of the document. Thirdly, the document should indicate that it is to be used if the maker loses mental capacity. Fourthly, a clear statement of the treatment to be refused and the circumstances in which this is to be refused should be set out.

16. At risk of repetition, the core features required are as follows:

i) *full details of the person making the advance decision including the date of birth, home address and any distinguishing features;*
ii) *the name and address of the person's GP and whether they have a copy of the document;*
iii) *a statement that the document should be used if the person ever lacks capacity to take treatment decisions;*
iv) *a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;*
v) *the date the document was written;*
vi) *the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence);*
vii) *the signature of the person witnessing the signature, if there is one.*

17. The insertion of the PEG, in the circumstances of this case, was an essentially life-sustaining treatment in circumstances where there was little, if any, prospect of meaningful recovery. In these situations, s25(5) and (6) MCA elevate the requisite safeguards. Advanced Decisions to refuse life-sustaining treatment should meet the following requirements at 9.24:

- *They must be put in writing. If the person is unable to write, someone else should write it down for them. For example, a family member can write down the decision on their behalf, or a healthcare professional can record it in the person's healthcare notes.*
- *The person must sign the advance decision. If they are unable to sign, they can direct someone to sign on their behalf in their presence.*
- *The person making the decision must sign in the presence of a witness to the signature. The witness must then sign the document in the presence of the person making the advance decision. If the person making the advance decision is unable to sign, the witness can witness them directing someone else to sign on their behalf. The witness must then sign to indicate that they have witnessed the nominated person signing the document in front of the person making the advance decision.*
- *The advance decision must include a clear, specific written statement from the person making the advance decision that the advance decision is to apply to the specific treatment even if life is at risk.*

- *If this statement is made at a different time or in a separate document to the advance decision, the person making the advance decision (or someone they have directed to sign) must sign it in the presence of a witness, who must also sign it.*

18. In some cases, depending on a patient's circumstances even modest intervention will be life-sustaining. For completeness the following paragraphs of the Code require to be set out:

> *9.25 Section 4(10) states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life.*
>
> *9.26 Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural mechanisms that control hunger and thirst and requires clinical monitoring. An advance decision can refuse ANH. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.*
>
> *9.27 It is very important to discuss advance decisions to refuse life-sustaining treatment with a healthcare professional. But it is not compulsory. A healthcare professional will be able to explain:*
>
> - *what types of treatment may be life-sustaining treatment, and in what circumstances*
> - *the implications and consequences of refusing such treatment (see also paragraph 9.14).*
>
> *9.28 An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth. Section 5 of the Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity to consent (see chapter 6). An advance decision can refuse artificial nutrition and hydration.*

19. Ms Dolan, who is extremely experienced in this area of the law, tells me it is relatively uncommon for lay people to prepare such Advance Decisions. There are few reported cases in the Court of Protection considering Advanced Decisions. This may support Ms Dolan's assertion as to their rarity but perhaps also testifies to their effectiveness; the objective of an Advance Decision is, after all, to avoid unwanted medical treatment **and** litigation.

20. Mrs Rushton's document, rather characteristically as I have come to know her in this Court, complied with the provisions fastidiously. In particular, the document was sent to her GP and kept on file. However, what she stated in the document is as follows:

> *"on collapse, I do not wish to be resuscitated by any means."*

21. She amplified this:

> *"I am refusing all treatment. Even if my life is at risk as a result."*

22. Addressing the applicability of her decision, she identified her aspiration in these terms:

> *"in all circumstances of collapse that put my life at risk, this direction is to be applied."*

23. As I have already foreshadowed, the initial insertion of the naso-gastric tube was arguably incompatible with Mrs Rushton's wishes. There can be little doubt, to my mind, that the insertion of the PEG was contrary to Mrs Rushton's written decision.

24. Ms Dolan has taken me to the clinical notes that provide the background to the decision making. It is plain, or at very least it appears, that the document was not available at the hospital. There is, in fact, no reason why it should have been. However, the existence of the document and the identity of the GP came to light. A telephone call was made to the GP at 10.25am of the morning of 26th Jan 2016. In response to a message, the GP contacted the ward. He told them he had checked the systems and that he knew Mrs Rushton and her family. The record of the call reads, "*the only ADR* (Advance Directive) *in place is in regards to do not resuscitate*." The GP is reported as having said that he had no knowledge of any other document. There was only one document in existence and, I must infer, that at some point in relaying its contents, it has been incorrectly interpreted. I have not been asked to investigate where responsibility lies for this and I do not intend to do so. Having heard from Mrs Rushton's family I have not the slightest doubt that she intended that her directive would have applied to the insertion of the PEG. The family is not critical of the hospital or the General Practitioner. They have approached this case and their mother's circumstances phlegmatically and have, throughout, kept her needs and their conviction as to her wishes, at the centre of the process.

25. Mrs Rushton's circumstances do however provide an opportunity for this Court to emphasise the importance of compliance both with the statutory provisions and the Codes of Practice, when preparing an Advance Decision. Manifestly, these are documents of the utmost importance; the statute and the codes provide essential safeguards. They are intending to strike a balance between giving proper respect and recognition to the autonomy of a competent adult and identifying the risk that a person might find himself locked into an advance refusal which he or she might wish to resile from but can no longer do so. The balance is pivoted on the emphasis, in the case of life-sustaining treatment, given to compliance with the form specified by statute and codes. The Court has highlighted the profound consequences of non-compliance with the requirements: ***W v M and S and A NHS Primary Care Trust [2012] COPLR 222; Re D 2012 COPLR 493.***

26. It perhaps requires to be said, though in my view it should be regarded as axiomatic, that the medical profession must give these advanced decisions the utmost care, attention and scrutiny. I am confident the profession does but I regret to say that I do not think sufficient care and scrutiny took place here. The lesson is an obvious one and needs no amplification. Where advanced decisions have been drawn up and placed with GP records there is an onerous burden on the GP to ensure, wherever possible, that they are made available to clinicians in hospital. By this I mean a copy of the decision should be made available and placed within the hospital records with the objective that the document should follow the patient. It need hardly be said that it will rarely, if ever, be sufficient to summarise an advance decision in a telephone conversation.

27. The family began to make their own enquiries. They concluded that Mrs Rushton's situation, which they had come to regard as parlous and contrary to her wishes, might very well continue for many years. They proved to be correct. A Dr Goldsmith, a consultant neurologist, was instructed. In November 2016 he concluded "*that Jillian Rushton was dementing prior to the head injury and that this dementing process involved many aspects of brain function*." He concluded that she was in a *"minimally conscious state"*.

28. It is unnecessary to burden this judgment with the full chronology of the intervening years. Ms Paterson who appears on Mrs Rushton's behalf today, through the Official Solicitor, has prepared a characteristically succinct and helpful chronology which I adopt in full to give context to the issues in this case:

Date	**Event**
20.11.16	JR was assessed by Dr Goldsmith, neurologist who concluded that she was in a minimally conscious state but that "*it is clear that she was dementing prior to the head injury and that this dementing process involved many aspects of brain function. This process would be ongoing. It is with the combination of age, evidence of prior dementing process plus current examination findings that cause me to conclude that her prognosis for any meaningful recover is dismal*…"
17.10.17	JR was assessed by Dr Goldsmith: *"The movements that Mrs Rushton now displays are all reflexive and there is no evidence of any conscious interaction. This is a deterioration from last year; although even in November 2016 any evidence of conscious interaction was minimal and one reflects that there is also a background dementing process which would forebode a deterioration in her state in any case…"* See lines 99-104
5.1.18	Instruction to conduct a SMART assessment sent to Karen Elliott from GTE Consultants
05.03.18-15.03.18	Karen Elliott undertakes a SMART assessment
15.4.18	Ms Elliot's SMART assessment report provided:

> *"…She did not demonstrate any behaviours indicating awareness of herself or her environment, but has primarily reflexive responses with some spontaneous but non-purposeful behaviours.*
>
> *It is understandable how her responses, while non-meaningful, could be interpreted as purposeful. However, through repeated extended assessment, exploration of reported responses and the inclusion of familiar stimuli, I do not believe the responses indicate purpose or awareness…"*

24.07.18	A best interests meeting held involving Mrs Rushton's three elder sons
21.9.18	Expert in neurorehabilitation instructed by CCG – subsequently notifies CCG that is unable to report promptly and instructions are withdrawn
18.10.18	Professor Wade instructed by CCG
Late Oct.-early Nov.18	Mr T Rushton states that dates offered by Prof Wade to assess JR are not convenient
14.11.18	Proceedings Issued
07.12.18	Professor Wade assesses JR
9.12.18	Professor Wade provides his first report
11.12.18	First Court of Protection directions hearing

29. As identified in the chronology above, Professor Wade, a professor in neurorehabilitation, was instructed. He gave evidence before me today. In response to Ms Dolan's questions he indicated that he was resistant to identifying Mrs Rushton's condition as "*a persistent vegetative state*" because he concluded that what was truly required was a holistic evaluation of her best interests, in the context of her wishes and feelings, in which her level of consciousness played a part. That approach, very much chimes with the guidance issued only a few days ago by the Royal College of Physicians and the BMA: **"Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent"**. At section 5 of that guidance, consideration is given to decisions concerning CANH in previously healthy patients now in a vegetative state or a minimally conscious state, following a sudden onset of brain injury. I am conscious that the phrase "*vegetative state*" is distressing to family members, but while it remains a medical term I am constrained to use it. The Guidance is, in my view, an extremely helpful piece of work which reflects the breadth of experience, both in the core group of representatives of the British Medical Association, Royal College of Physicians and General Medical Council as well as the multi-disciplinary advice that was drawn upon. I take the opportunity in this judgment to highlight the following:

> ***5.1 Clinical assessments***
>
> *Where patients are in Prolonged Disorder of Consciousness, PDOC, (i.e. for longer than four weeks) following a sudden-onset brain injury, providing accurate prognostic information is a very important part of the decision-*

making process. Assessing levels of awareness – and in particular the prospect of it increasing – however, is not a simple task and there is no single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame intentions and interact with others. These observations need to be repeated over a period of time, with specialist analysis of the results. It is essential, therefore, that these patients have a thorough, expert assessment according to the RCP guidelines to provide a detailed evaluation of their level of awareness of themselves or their environment and to record any trajectory towards future recovery or deterioration.

There may be some cases in which there is clear evidence that the findings of detailed assessments will not affect the outcome of the best interests decision because, for example, even the most optimistic prediction of recovery would not constitute a quality of life they would find acceptable. Where this is the case, a decision can be made before these assessments have been completed.

In most cases, while these investigations are being made, careful consideration should be given to reducing or stopping sedating drugs, to ascertain the extent to which they are reducing responsiveness (if at all). This may involve risks, for example of pain or seizures, which can be distressing for those close to the patient. It is crucial that doctors clearly explain the steps they are taking, why they are taking them and what to expect during that time. If withdrawal or reduction of medication is likely to have significant consequences for the patient, the doctor will need to weigh up the balance of benefits and harms between optimal assessment conditions and adequate symptom-control. This will include an assessment of how important a clear diagnosis of permanent VS versus MCS would be for the patient in terms of the best interests assessment.

Diagnosis and prognosis

The perceived importance of obtaining a precise and definitive diagnosis has reduced over time, as it is increasingly recognised, by clinicians and the courts, that drawing a firm distinction between VS and MCS is often artificial and unnecessary. In practice, when assessing best interests, information about the patient's current condition and prognosis for functional recovery and the level of certainty with which these can be assessed is often more important than achieving a precise diagnosis.

30. These paragraphs are apposite. The perceived importance of a definitive diagnosis has reduced over time. As is increasingly recognised by clinicians and the Courts, drawing a firm distinction between vegetative state or a minimally conscious state is often artificial and unnecessary. In practice, when assessing 'best interests' and analysing the information relating to the patient's current condition and prognosis for cognitive recovery, the level of certainty to which these can be assessed is often more important than an actual diagnosis. Many patients would want CANH continued until there is a clear sense of the level of recovery that can be achieved. In these patients the prognosis is important as it allows those concerned to make best interest decisions.

For example, they may have refused treatment if the Prolonged Disorder of Consciousness (PDOC) assessment showed that they were likely to be left permanently unconscious, but not if they were likely to regain consciousness.

31. When gently pressed by Ms Dolan, Professor Wade was clear; if one was to attach a label, the correct one is "*persistent vegetative state*," both because of the endurance of the condition and because of the ongoing twin pathology of advancing dementia. He considered that she was most probably beyond pain and beyond awareness. Although her son, Tim Rushton, considered her to be responsive, Professor Wade was certain that her movements were merely reflexive. However, he stated with what I consider to be great sensitivity to the family, that even with patients in this level of unconsciousness, there is a response to mood and environment, to darker and lighter rooms and to music. I have no doubt that Mr Tim Rushton has interpreted these as a level of awareness that is in truth no longer present.

32. One of the brothers, Hugh, told me candidly and poignantly that his mother "*had been gone for some time*." It requires to be said that simple expression, in such plain terms, is entirely consistent with the medical evidence and its ultimate conclusion.

33. This is a distressing case, as is any involving the withdrawal of CANH where there is a dispute. The family have in their different ways been able to bring Mrs Rushton into this court room today. They have revealed her character, her personality, her capacity for forthright expression. They, each of them, in their different ways, made it clear to me that she would not have regarded her present situation as tolerable. Whilst I have no doubt that she would understand the commitment of her son, Tim and his profound resistance to letting her go, I have equally no doubt that she would want to be let go and I have no hesitation in concluding that it is my responsibility to respect this.

34. I have read various statements from a variety of people concerning Mrs Rushton's life, as to what her wishes would have been in these circumstances. I must say, I have heard sufficient from Mr Tim Rushton and his brother, Hugh, to be clear, that Mrs Rushton would have hoped that her wishes in her advance decision would have applied to her present situation. I cannot easily contemplate circumstances in which the views of an adult with this degree of disorder of consciousness could be communicated more volubly or unambiguously.

35. I must go further and evaluate the care plan which in this case is particularly difficult. The reality is that for the past 12 months, Mr Tim Rushton has cared for his mother almost exclusively. I do not think that he is any way motivated to shut out the family or indeed the medical professionals whose visits have been reduced to a bare minimum. I note, however, that Dr Goldsmith in his most recent report, noted Mrs Rushton's deterioration and I do not doubt that this was evident to Mr Tim Rushton. I strongly suspect he was scared of losing his Mum and so battened down the hatches as best he could to try and prevent it. This is certainly the view within the family.

36. There is a rigid, inflexible regime of care at the moment. It must be said, that is obvious that Mrs Rushton has been very well cared for. Ms Paterson, on behalf of the OS, submits that the present circumstances do not promote or sufficiently protect either Mrs Rushton's autonomy or her dignity. Dignity at the end of life is elusive both conceptually and practically. For Mrs Rushton's life to conclude with dignity, she needs what all of us would need in that situation, peace, care, proper medical

attention and the presence around her of those she has loved. I have concluded that though she would have wished to die at home, true respect of her dignity can only be achieved in a hospice and under a regime which, as her son Hugh says, *"allows her some space and privacy".* Tellingly, in my judgment, insightfully, Mr Hugh Rushton went on to say that his mother needed to be in a place where she was no longer "*prodded and poked*" by those undoubtedly well intentioned to care for her, but rather she needed a place *"to rest"*. I entirely agree and consider that the care plan contemplates precisely this. Accordingly, I endorse it.

Post Script

I delivered this Judgment, ex-tempore, on 21 December 2018, at the conclusion of the hearing. I delayed its publication to protect Mrs Rushton's privacy at the end of her life. I have today perfected the judgment (on the principles of **Piglowska v Piglowski [1999] UKHL 27**) and am now placing it in the public domain. As always, in these cases, the hearing took place in open court. At the conclusion of the hearing I indicated that I would delay publication until a month after Mrs Rushton's death in order to give her family some privacy to grieve. **(see M v Press Association [2016] EWCOP 34; V v Associated Newspapers Limited [2016] EWCOP 21; Re S (A child) (Identification: Restrictions on Publication) [2004] UKHL 47.** Last week I heard that Mrs Rushton had died. Her family have my condolences.