

Neutral Citation Number: [2017] EWHC EWCOP 23 (Fam)

Case No: COP 13007536

IN THE COURT OF PROTECTION

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 30/10/2017

Before:

MR JUSTICE HAYDEN

Between:

SALFORD ROYAL NHS FOUNDATION TRUST

Applicant

- and -

(1) MRS P

Respondent

(by her litigation friend, the Official Solicitor)

	(2) Q														
-				-			-			-			-	-	

Joseph O'Brien (instructed by Hill Dickinson) for the Applicant Vikram Sachdeva QC (instructed by the Official Solicitor) for the First Respondent Victoria Bulter-Cole and Annabel Lee (instructed by Irwin Mitchell LLP) for the Second Respondent

Hearing dates: 16th, 17th, 18th October 2017

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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HAYDEN

This judgment was delivered in public. 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. I am concerned here with an application to declare the best interests of a 72 year old woman who, following a fall in December 2016, now lacks the mental capacity to communicate her own wishes and feelings in respect of life sustaining medical treatment. I shall refer to her throughout this judgment as Mrs P. The application is brought by the Salford Royal NHS Foundation Trust who seek a declaration that it is in Mrs P's best interests to receive clinical treatment including clinically assisted artificial nutrition and hydration (CANH) by way of a PEG. There are ancillary declarations which may follow dependent upon my judgment on this primary issue. They do not require to be set out here.
- 2. There is no dispute that Mrs P is in a Minimally Conscious State (MCS). As the hearing has progressed it has been agreed by all the parties, on the basis of clear evidence, that she is at the lower end of the spectrum of MCS. I have heard evidence on this issue from Professor Derick Wade, Consultant in Neurological Rehabilitation, instructed as an independent expert in this application and Dr Krystyna Walton, also a Consultant in Neurological Rehabilitation, employed by the Applicant Trust.
- 3. As will emerge from my analysis below the preliminary question of whether Mrs P has the capacity to make the decisions in contemplation is, sadly, not difficult to resolve. Both Professor Wade and Dr Walton agree that she has a disorder of the mind and brain. This is brain damage sustained in December 2016 and accordingly meets the requisite test pursuant to Section 2(1) of the Mental Capacity Act ('the 2005 Act'). It provides:
 - 2 People who lack capacity
 - i) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.
- 4. Both the experts also agreed that Mrs P was not able to understand the relevant facts nor, inevitably, to hold them within her memory. She is unable either to communicate or to arrive at any reasoned judgment. Furthermore, they agreed and everybody accepted, there is no prospect of her regaining the mental capacity to make decisions about her health and wellbeing. In this inquiry the doctors were considering the 'specific questions' required by Section 3 of the 2005 Act.

Background History

- 5. The detail of the background history requires to be set out. In doing so, I have identified its salient features, taking them from a variety of sources. These include the reports of Professor Wade, Dr Walton, and the written and oral accounts of the many family members from whom I have heard during the course of the application.
- 6. Mrs P's daughters reported that she had developed headaches two or three weeks before what has become known as the 'index event'. They reported that she eventually saw her general practitioner about this because it was constant and worsening and causing her to vomit. The GP recommended that she attend the

emergency department at the hospital, but she decided not to. It is a feature of Mrs P's medical history that she frequently ignored her doctor's advice. That is her right and she is by no means alone in exercising it. Her daughters reported that on Tuesday 13 December 2016 she was so concerned about her vision, and whether or not the headaches presaged some damage to her eyes, that she took a taxi for a one hour journey to visit the Manchester Eye Hospital. Family and friends tell me that Mrs P was very concerned about losing her vision which, understandably, she associated with restriction on her independence. I formed the impression that her preoccupation with this was deep seated and rooted in an exaggerated fear rather than a real medical risk. The GP records note an attendance on December 12 2016; it concerned a fall three weeks previously and it states that she wanted an early appointment at the eye hospital. A friend's husband who, conveniently, was a taxi driver transported her and stayed with her for some time at the hospital.

- 7. The hospital records at the Manchester Eye Hospital showed attendance on 13 December 2016. Mrs P is recorded as having fallen in a car park on 26 November 2016, hitting the left side of her forehead on the ground. There was no loss of consciousness. A few days later she had had three episodes of vomiting, and she continued to have pain at the back of the skull and on the left of her head. She had become less alert and more forgetful. Initial examination did not reveal anything specific. She had a CT brain scan, and although the findings were not definitive, they were suggestive of a resolving subarachnoid haemorrhage. It was noted that she had high blood pressure, requiring treatment. She was admitted from the eye hospital into Central Manchester University Hospital, Manchester Royal Infirmary. She was fully clerked in on the next morning. The CT brain scan reported in the notes stated "the sylvian fissure is obtunded bilaterally. Sulci seen well. Prominence in temporal horns. Probable high density in the parietal suture. Appearances are suggestive of resolving subarachnoid blood." At that time she was slightly confused but otherwise well.
- 8. On 14 December Mrs P had a lumbar puncture. The cerebrospinal fluid showed changes typical of a past subarachnoid haemorrhage. She was referred to the neurosurgical department. Later on 14 December 2016 she suddenly deteriorated. It was noted that she appeared to be following commands but that she had "expressive dysphasia". There was no unilateral motor loss. She appeared to have visual and sensory neglect on the left side. She appeared frustrated. The CT brain scan undertaken shortly afterwards showed no significant change from the previous one. The full report read "No significant change compared to the previous examination performed the day prior. Again, the sylvian fissure is not clearly identified but there is preservation of the shift. The ventricles and basal cisterns are similar in configuration. Periventricular low densities are present in keeping with chronic small vessel disease."
- 9. The next morning Mrs P still had a headache, but she was not confused, although slightly sleepy. On 15 December 2016 she had a magnetic resonance angiogram. The report of the MRI angiogram confirmed changes consistent with previous subarachnoid haemorrhage on the right. There was evidence of an anterior communicating artery aneurysm. There were patchy white matter signals in both cerebral hemispheres and in the pons. She was admitted to the intensive care unit on 16 December 2016.

- 10. Her daughters reported that, 'fairly typically' for their mother, she had not informed them of her illness, and they did not see her until Wednesday 14th December. At that time she was disorientated and confused, not able to move around very much and not eating. She was however able to speak in grammatically correct sentences. The one thing that she said repeatedly and which has been emphasised and investigated before me was "I want to go home".
- 11. The Salford Royal Hospital notes record the arrival at the Emergency Department at approximately 21:30 hours. At that time Mrs P was unconscious with a Glasgow Coma Scale score of 3/15, which I have been told records the lowest level of consciousness available. She was taken immediately to theatre. The clinical note records that the diagnosis was of acute subarachnoid haemorrhage and hydrocephalus. She was intubated prior to arrival. In theatre she had insertion of an external ventricular drain, and of an intracranial pressure monitoring bolt. She was then transferred to the Intensive Care Unit. The history then recorded a deterioration in her level of consciousness early. On 16 December unequal pupils were observed. There followed a further CT brain scan which showed evidence of fresh subarachnoid bleeding, hydrocephalus and a frontal intracranial haemorrhage. A CT angiogram revealed a forward pointing anterior communicating aneurysm. In the intensive care unit she was on advanced respiratory support. A nasogastric feeding tube was inserted on 17 December. She was noted to be hypotensive and bradycardic at 04:10 hours.
- 12. There is an entry in the hospital records on 17 December 2016, in the evening, concerning a discussion between the clinicians and the two daughters. It is recorded:

"they explained that their mother had previously expressed a wish not to be kept alive if severely handicapped, especially if mental function affected severely."

- 13. This communication of what were said to be Mrs P's views is the first mention of the issue which has been the focus of this hearing. I note that it was said very early on, following her collapse. I observe, also, that it was spontaneous, in the sense that, the issue was raised by the daughters and not medical staff. For reasons which I will return to in more detail below I consider it to signal authenticity, by which I mean more likely to be an accurate reflection of their mother's own views and beliefs.
- 14. On 18 December Mrs P was stable and being ventilated. She was also on sedation. On the 19 December it was noted that both pupils were reacting to light. Sedation was continued. In the afternoon on the 19th she went to the angiography suite. The imaging report read:

"Cerebral angiography demonstrated an aneurysm complex arising at the left A1/A2 junction. The main aneurysm measured up to 10 mm in diameter with a nipple at its apex and was presumably the site of rupture. There are number of lobulations seen at the base of the aneurysm and there is also a adjacent daughter sac projecting inferiorly. The main aneurysm was coiled using the balloon remodelling technique. A 4 x 11 mm Septre XC balloon was placed via the left

pericallosal artery. Placement of a balloon within the vessel itself was partially occlusive however the aneurysm was coiled and at the end of the procedure the aneurysm appeared protected with normal flow seen in both A2 vessels. Note was made of a absent right A1 segment on the CT angiogram. Angioseal device used to secure the left groin."

15. The following day, 20 December 2016, Mrs P underwent a further CT brain scan and this was reported:

"Compared to the most recent study, there has been interval coiling of the ACOM aneurysm and insertion of a right frontal EVD with the tip at the foramen of Monroe.

There is persistent scattered subarachnoid blood over both convexities, in the subfrontal region, and interhemispheric region. Moderate amount of layering blood demonstrated within both lateral ventricles. There is also a small left parafalcine subdural. Although there has been redistribution, the overall volume of intracranial blood is stable, or perhaps slightly reduced. The previously demonstrated ventriculomegaly has improved. No significant mass-effect and no brain herniation.

Low-attenuation in the left anterior cerebral artery territory (series 2, image 10) surrounds a small haematoma, but is suspicious for a small area of infarction.

Comment: Interval coiling of previously demonstrated a common aneurysm and insertion of a right frontal EVD. Stable or slightly reduced volume of haematoma in multiple compartments. Low attenuation in the left ACA territory suspicious for a small infarct."

- 16. Whilst I have thought it important to review the circumstances of the presenting incident and its early aftermath, it is unnecessary for me to burden this judgment with an account of Mrs P's treatment and presentation in the months that followed. Dr Walton and Professor Wade have, in preparation for this hearing, been able to agree a number of significant facts which obviate the need for that exercise. These require to be set out. I have adjusted them slightly in the light of the oral evidence:
 - i) Mrs P is at the lower end of a minimally conscious state;
 - ii) MRS P has not had any significant clinical medical problem. At times when it is not possible to re-insert the nasogastric tube or confirm its placement without recourse to chest x-ray, intravenous fluids are administered to maintain hydration;

- iii) The continuing problems with the nasogastric tube have an impact upon MRS P's medical state. For example MRS P becomes slightly dehydrated if the nasogastric tube is disconnected for any length of time. This impacts upon MRS P's care needs;
- iv) The dominant active care need is for careful management of the nasogastric tube and her feeding and hydration. This places a considerable strain upon the nursing and care staff. It also causes considerable distress to MRS P. Care staff need to be alert to the risk of the tube being pulled about and to managing the situation. There needs to be a particular care plan in relation to the 'Posey' mitten, which is on the left hand and used to restrain it. The objective is to try to restrain Mrs P from pulling out the NG tube which is an irritant to her;
- v) Mrs P has a splint for her right wrist and hand which needs to be in place and taken off on a regular basis. She has a foot drop splint on her right ankle which also needs to be put on and taken off regularly. The right foot/ankle splint has caused slight pressure damage to her skin and this is reviewed regularly by nursing and therapy staff;
- vi) MRS P has a range of regular nursing care. She needs to be hoisted from her bed into the chair which requires the assistance of two people, needing sensitive careful care of her tracheostomy. She needs management of the bowels and bladder (due to double incontinence);
- vii) There will be no further change in her underlying neurological and neurophysiological state. There will be no significant improvement in terms of underlying levels of awareness and responsiveness, and in terms of ability to control motor movements, think, remember, swallow, speak or otherwise communicate;
- viii) If it is agreed that a gastrostomy tube is preferable to a nasogastric tube, and her left hand does not need to be restrained in the mitten, then under these circumstances there might be some functional movement of the hand. However this would be limited in quality and quantity and will not enable independence in any respect of personal care such as washing her face.
- 17. As foreshadowed above, both Professor Wade and Dr Walton ultimately agreed, in evidence, that the cerebral imaging studies revealed extensive widespread damage consistent with pre-existing cerebrovascular disease, the effects of a not entirely resolved hydrocephalus and areas of focal infarction. The range of Mrs P's reactions, which have inevitably been subject to different interpretations during the cause of her time in hospital, it is now agreed are limited to reactions to specific stimulation. There are no reported spontaneous behaviours consonant with awareness. The one exception to this is Mrs P's repeated removal of her nasogastric tube. This has occurred on approximately 50 occasions. Counsel have explored whether this might be indicative of her views in relation to treatment more generally. However, Dr Walton, supported by Professor Wade, explained that this was a response to the irritation of the NG tube. Mrs P simply does not have the capacity to formulate the kind of wishes that it was considered this action might be an expression of.

- 18. The potential for improvement in Mrs P's circumstances is very limited but it should not be understated. Dr Walton and the nurses involved in rehabilitation and care, feel that a transfer to a nursing centre would provide Mrs P with a calmer environment than the acute clinical ward where she is presently based. They also highlight Mrs P's obvious reactive sensory pleasure on being bathed or showered and her ability to smile at those who smile at her. Professor Wade has described this as a 'primal reaction', Dr Walton sees it as more than that but acknowledges that it is 'difficult to define pleasure in this context'. She has no recognition of any of her family, friends or carers. I should like to observe here that I have found the nurses and rehabilitative staff involved in Mrs P's care to be personally and professionally impressive.
- 19. Dr Walton considered that this limited potential nonetheless pointed towards the insertion of a PEG tube which would obviate the need for the NG tube. She considered, on balance, that nutrition and hydration should be continued. Professor Wade took the contrary view i.e. that the insertion of the PEG and continued nutrition and hydration could no longer be said to be in Mrs P's "best interests". In his report, dated 21 September 2017, Professor Wade observed as follows:

"Cerebral imaging studies have shown extensive widespread damage consistent with pre-existing cerebrovascular disease... the effects of hydrocephalus, and areas of focal cerebral infarction. Most observations made indicating awareness have arisen in the context of specific stimulation. There are no reported spontaneous behaviours indicating awareness other than attempts to remove distressing stimuli from her nasogastric tube and a splint."

I conclude that she is in a lower level of a minimally conscious state. On the balance of probability any experience she has will be unpleasant, and there is little evidence of pleasurable experiences. There is no prospect of any significant improvement in her level of cognitive or motor function and she will never regain the ability to communicate her decisions and wishes or anything else."

- 20. Dr Walton, in her evidence, did not disagree with any of this. In the months since the index event (i.e. the onset of this condition) it is clear that the improvements hoped for initially have not been realised. Whilst there are nuances of interpretation between the lay parties and the nurses, the overwhelming picture is one of very minor improvement, in the first one or two months, followed by a plateau-ing out, at best, or a detectable deterioration during the last six months. The medical consensus is that any further progress by Mrs P is compromised by a number of factors: her age; vascular disease; her likely pre-existing general cerebro-vascular disease (attributable to life style) and the minor continuing hydrocephalus. These factors all militate very heavily against the recovery of cognitive function even as low as the capacity to make simple choices or request the most basic assistance.
- 21. When Mrs P's daughter, Q first resisted the Trust's application, I have no doubt at all that she was highly motivated to protect her mother and to give effect to what she perceived to be her mother's wishes. In the early stages of this application the clinical

position was, as I believe the family recognise, much less clear than it is now. Views and opinions within the family have shifted. There has plainly been real reflection which has, at very least, ameliorated the views of those within the family who instinctively supported the Trust's application, not least of their reasons being, in my judgment, that they considered the prognosis to be unclear. Sad though it is to acknowledge, all involved have had gradually to recognise that no drug or therapeutic treatment will improve Mrs P's level of awareness and responsiveness. No surgical treatment is available. Mrs P will remain doubly incontinent. The possibility of a ventriculoperitoneal shunt treating Mrs P's residual hydrocephalus is contra-indicated by her medical condition and has been discounted by the neurosurgeon and the neurological specialists. The prospect of the tracheostomy being removed is, as I assess the evidence, vanishingly remote. Potential life expectancy for Mrs P in her present condition, whilst heavily speculative, is agreed to be in the region of three to five years.

- 22. Thus, whilst all the essential clinical facts seem to be agreed upon, their interpretation i.e., evaluating how they highlight where Mrs P's "best interests" lie, remain the subject of debate. In my judgment, the disagreement arises from Professor Wade and Dr Walton's efforts to identify what Mrs P would have wanted for herself in this situation. Though they have been discouraged by the lawyers from embarking upon this line of enquiry, it seems to me that the lawyers' restraint is misconceived. It is intrinsic to the concept of the differential diagnostic method that patient history and views are listened to; it is also the obligation of every doctor to obtain his patient's wishes and where possible, consent. These are skills refined and honed over the years The doctor will instinctively try to consider the patient holistically. of practice. Hearing evidence from doctors I have recognised that this process becomes so intuitive that it can be an almost unrecognised professional reflex. In these difficult cases the Court should not be deprived of this experience and expertise. I note, wryly, that both Professor Wade and Dr Walton unshackled themselves from their restraints in their respective reports.
- 23. All this said, it is ultimately a matter for the court to determine, if it can, what a patient in Mrs P's position would have wished for herself. It requires to be emphasised that both Dr Walton and Professor Wade unhesitatingly agreed that if Mrs P's wishes could be ascertained in this process they should be determinative of the outcome. This, they considered, would be conclusive of her best interests.
- 24. It is not that the judge or the lawyers are somehow better placed to undertake an evaluation of a patient's wishes than the doctors; it is simply that the Court process provides an opportunity to survey the broader landscape of an individual's life in a way that the medical profession, in the course of clinical practice, is simply not afforded. At this hearing I have had the opportunity of listening to Mrs P's sisters, daughters, partner, friends and two of her grandchildren. In the months since this application commenced there have been different, sometimes opposing, views expressed by the family. During the course of the hearing there has been a marked convergence of perception as the family has listened to the different perspectives. I have had the real opportunity to get to know something of Mrs P through the evidence of her family and friends. In this case, the very fact of the disagreements and tensions between them has led, paradoxically, to a clearer picture of who Mrs P is and what she would want. It is plain that Mrs P loved and enjoyed the company of those

closest to her. I can, if I may say so, quite see why, they are a remarkable, articulate, well informed, intelligent group of people. They have also at times been amusing, mostly intentionally, though sometimes not.

Legal Framework

25. The Mental Capacity Act, Code of Practice contain provisions relating to the withdrawal of life-sustaining medical treatment at paragraphs 5.31 and 5.33. In **Briggs v Briggs [2016] EWCOP 53** Charles J made the following observation at paragraph 75:

"I have not expressly mentioned the Mental Capacity Code of Practice which addresses decisions about life-sustaining treatment at paragraphs 5.31 to 5.33. This is because they are addressed in the Aintree Hospitals case that lies at the heart of my analysis and conclusion."

- 26. The key aspects of Charles J's analysis require to be highlighted:
 - "55. The Supreme Court in the Aintree Hospitals case also make it clear that a holistic approach is to be taken to the application of the MCA and its best interests test, see paragraph 26 cited above, and paragraph 39 which draws together other points made in the judgment in the following terms (with my emphasis):
 - "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 on what his attitude would be."
 - "56. In my view, the factors that will give indications as to what the individual P wants include the interests of other people who P would have been likely to take into account and so, for example, many if not most Ps when they had capacity would have taken into account their relationships with others (e.g. spouse and children), how they think they their children should be parented and the impact on those closest to them of what they decide to do."
 - "57. Pausing there, it is clear and important to stress that a conclusion on what P would have done is not determinative of the MCA best interests test and so, by stating that the MCA enables the court to do for the patient what he could do for himself if of full capacity, the Supreme Court is not saying that a conclusion on what

the patient would have done is decisive. The test is not a "what P would have done test", it is a best interests test and so a test that requires the decision maker to perform a weighing or balancing exercise between a range of divergent and competing factors."

27. Paragraph 57 is particularly important here in the light of the evidence that I will consider below. If I am satisfied as to what course Mrs P herself would have adopted it does not follow axiomatically that this should be regarded as in her best interest. I am still required to consider, balance, weigh all the divergent features and competing factors, some of which are in different conceptual spheres and not easily receptive to a balancing exercise. Charles J also notes:

"58. In that exercise the force, clarity or certainty of conclusions that found competing factors will affect the weight to be given to them and that weighing exercise is not a linear or binary exercise.

- "59. The approach of the Supreme Court shows that the paragraphs in the judgment of HH Judge Hazel Marshall QC in Re S and Another (Protected Persons) [2010] 1 WLR 1082 cited by Hayden J at paragraph 27 of his judgment in Re N [2016] COPLR 88) are correct and so support the view that P is at the very centre of the decision-making process. I gratefully adopt this citation which was directed to a very different type of case but in my view it applies to all applications of the best interests test. It is: "
 - 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 interest in all the relevant circumstances, including those wishes."
- 28. In addressing this challenge Charles J has offered the following reasoning which I have found to be helpful:
 - "60. The weight to be given to a conclusion on what P would have done for himself or herself in the past or in the present if P was able to make the decision will be very fact sensitive. For example:

- "i) P's history may show that he or she has made a series of damaging investment or lifestyle decisions and so although if they had capacity they would be likely to do so again the court (or other decision maker) can conclude that it would not be in their best interests for such a decision to be made on their behalf,"
- *ii) it is not uncommon that what P would have wanted and would now want is not an available option,*
- iii) it is not uncommon that very understandable expressions of present wishes and feelings "I want to go home" would not be made if P was able to weigh the existing competing factors by reference to P's beliefs and values, and in any event are not in P's best interests, although current expressions of wish can inform which of available alternatives has the best chance of being successfully implemented,
- iv) the point that an individual and a court cannot compel a doctor to give certain types of treatment is a factor in cases relating to life-sustaining and other treatment (as an individual can only exercise his or her right of self-determination between available choices), and
- v) the existence of clinical conditions, physical illness and the types of life-sustaining treatment (e.g. resuscitation or treatment in intensive care) and the pain or loss of dignity they cause can be highly relevant factors in reaching a conclusion contrary to the evidence of P's family that P would have wished treatment to continue (see for example NHS Trust v VT [2014] COPLR 44, a decision of Hayden J)."
- 29. Ms Butler-Cole, who appears on behalf of Q, has conveniently distilled what she submits are some uncontroversial principles to be taken from the evolving case law. I agree. Though at risk of repetition I think it is helpful to incorporate them here concisely, having introduced a few amendments of my own.
 - i) The sanctity of life is not an absolute principle, and can be outweighed by the need to respect the personal autonomy and dignity of the patient: <u>Aintree v James</u> [2013] UKSC 6 at [35];
 - ii) There is no prohibition to conducting a best interests analysis of the continued provision of CANH even though MRS P is not in a vegetative state: <u>W v M [2011]</u> EWHC 2443 (Fam) at [102] per Baker J;
 - There can be no further guidance beyond the wording of s.4 other than that "decision makers must look at his welfare in the widest sense, not just medical but social and psychological; 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 are interested in his welfare, in particular for their view of what his attitude would be." Aintree at [39] per Baroness Hale.
 - iv) Where the patient's condition may improve, a best interests decision may be based on the 'best case scenario' as advised by the relevant clinicians and experts: <u>Briggs</u> overview at (25) per Charles J;

- v) It is incumbent on the court fully to investigate and consider the values and beliefs of the patient as well as any views the patient expressed when she had capacity that cast light on the likely choice the patient would have made and the factors that the patient would have considered relevant or important: <u>M v N</u> at [70] per Hayden J, <u>Briggs</u> at [54] per Charles J;
- Where the patient's views can be ascertained with sufficient certainty, they should generally be followed (<u>Briggs</u> at [62] per Charles J) or afforded great respect (<u>M v N</u> at [28] per Hayden J), though they are not automatically determinative. '...if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life. <u>Briggs</u> at [62ii] per Charles J.'...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.' <u>M v N</u> at [32] per Hayden J;
- 30. What emerges from the family's evidence is that Mrs P was headstrong, frequently combative, effervescing with ideas and projects. I see the same characteristics in both her daughters and sisters. Mrs P loved a crusade; she campaigned locally for the preservation of significant regional monuments. Predictably, she was successful. She listened regularly to local radio, believing passionately in what might be called 'localism' which I understood to emphasise the importance of communities maintaining cohesion and cooperation beyond the writ of the politicians. She loved history; her 'much younger sister' (as she reminded me she was, though she had no need to) volunteered in her evidence, apropos of nothing, her very fond recollection of Mrs P as a young English literature undergraduate reading her Anglo Saxon primer. She volunteered this apparently random recollection with almost palpable affection and pride. It is an image which conveys quite a lot, revealing Mrs P as both intellectually disciplined and curious. It has stayed in my mind.
- 31. Inevitably, there was another side to Mrs P. Like most of us, her weaknesses are a different facet of her strengths. Notwithstanding her diagnosis of chronic obstructive pulmonary disease (COPD), she continued to smoke heavily. A Methodist and teatotaller, she discovered, in her 40s, the pleasures of the grape which she came to with the zeal of the convert. She drank rather too much and rather too frequently. Her partner, Z, told me how he missed sitting up with Mrs P late into the night, drinking whilst he, largely unsuccessfully (he told me), tried to change her opinions on the political issues of the day. Movingly, he told me that he realised, as he put it, 'he was always going to be second fiddle to Mrs P's husband' but he continued bravely 'I loved her and miss her a lot'. It is important that I interpose here that whilst some months ago Z supported the application he had now come to believe that Mrs P would have hated her present predicament. She is 'not there anymore' he told me. He had concluded, following very great care and reflection, in my assessment, that Q's resistance to the Trust's application was now entirely appropriate. He confirmed that he had seen no change or improvement in Mrs P's condition. This accorded with the medical evidence. I had the very real sense from Z that whilst he would prefer, for himself, to keep Mrs P alive, even in her parlous circumstances, he was absolutely clear that she would not have wished it. Nobody listening to Z's evidence could fail to have been moved by it. I found it compelling.

- 32. Shortly before the hearing two of Mrs P's three sisters wrote to me stating that they did not want to give evidence and had come to the view that it was for the Judge and the doctors to decide. They feel, with some justification in my view, that Q effectively cut them out of any proper consultation when she decided to oppose the Trust's plans. I think Q was clumsy and insensitive in her approach. However, her aunts might like to reflect, that which I am sure they will know, namely that the grieving process in these very sad circumstances does not begin with death, but long before it. In their own way, each of the family members has described how they have begun to let go of Mrs P. I do not doubt that this is both natural and healthy. I highlight it here only because I would press the aunts to reflect on the fact that Q was taking her decisions in the white heat of grief and accordingly will not have been at her most rational. I am very pleased that the sisters changed their minds and decided to give evidence.
- 33. In my summary of the medical history (above) I commented how Mrs P decided to travel to hospital without informing her family of her own concerns for her health. Though Mrs P regularly spoke in public and could be gregarious she was immensely private about her own health. She never, for example, took her medication in front of people. One of her sisters told me how she would always take her medication discretely in the bedroom. She would not talk about her health issues and she would brook no criticism of her smoking habits. Her sister told me that she considered Mrs P was embarrassed by her own failure to stop smoking. All agreed that her insistence on privacy was a feature of Mrs P's determination to present a strong face to the world. She recoiled from revealing her faults or short comings.
- 34. Q, as I have stated above, informed the medical staff very early on that her mother would not have wanted the indignity of her present circumstances. She felt that some of the nursing staff judged her adversely for this. Sometimes her sense of being disapproved of prevented her from going to see her mother whom she had by this stage realised was unaware of her presence. These very difficult circumstances often provoke strong moral and theological reactions in others. Having commended the staff above I am bound to say that I do not consider Q's anxieties about some of the nursing staff's reaction to her to have been entirely misplaced.
- 35. Q told me in evidence that there had been a number of occasions when her mother had made it clear to her that she would not have wanted to prolong her life through medical treatment. Her religious beliefs, which changed and developed throughout her life, left her with a sense of consolation that she would be reunited with people dear to her after death. She told Q that she was not afraid of dying. Given that she and her mother were in regular email correspondence Q was confident that some of these views might have been expressed in her undeleted emails from her mother. Accordingly, she began a search. She told me that this was extensive and took her a long time. She found an email dated 13 May 2013. Following some superficial domestic exchanges is the following, which I record in full:

"Did you see that thing on dementia? Made me think of Dad and what a travesty of life his last years were and all the sadder as he had such incredible talent. You know I miss Mum everyday and still talk to her but it is a comfort that she went quickly and I am still haunted by how he ended up... Get the pillow ready if I get that way!... Love Mum"

- 36. Inevitably, this email has been given much focus by the family and in this Court room. All agree that Mrs P was deeply distressed by the decline and death not only of her father but of her husband. Mr Sachdeva QC, who represents Mrs P through the Official Solicitor, has tested the meaning of this email in cross examination. Mr O'Brien, on behalf of the Trust has done the same. Both have suggested that this email might only be regarded as recording one of those casual throw away remarks that we all make from time to time and are ultimately meaningless. 'Take me out and shoot me' is an example settled upon. It is important to emphasise that as this case evolved and both the medical evidence and lay evidence began substantially to converge, the advocates tested the evidence in an objective, sensitive and entirely non-adversarial manner.
- 37. The context of this email seems to me to be significant. It was written by Mrs P having watched a television programme about dementia. This triggered her recollection of her father's death which it is agreed remained a source of great sadness to her. The communication does not therefore exist in a vacuum but in the specific context of her view of life without consciousness or thought. That she identifies, as 'a travesty'. Moreover, so confident was O that her mother would have expressed this view in writing at some point that she trawled three years of undiscarded emails before finding it. This to my mind gives great credibility to Q's assertion that this was an issue that Mrs P had mentioned with some regularity. It is in this context that I find it to be a powerful indicator of Mrs P's own wishes. Reinforcing this are her own actions, concealing her health issues and deliberately not informing her family about them. I also heard from Mrs P's neighbour, a fellow sufferer with lung disease, who told me how they had both discussed how they would not like to linger with that illness. Thus, looking at Mrs P's life as a whole, I find the email to be reflective of her determination to preserve her independence, her privacy and her autonomy. Her expressed anxiety about losing her vision was primarily, said Q, about her fear of losing her independence. I agree that this was most likely.
- 38. Though it was not the subject of great focus in the evidence, Mrs P's husband, as I have mentioned, also sustained a debilitating illness and was confronted with end of life choices, which Mrs P supported. This led Mr O'Brien to suggest that a forceful articulate educated woman like Mrs P, who had experienced the diminishment of her loved ones at the end of their lives and who had found it intolerable, would have prepared an Advanced Decision pursuant to the Mental Capacity Act if she had truly intended that treatment should be discontinued in these circumstances. I have given that proposition thought but, during the course of exchanges, I reminded Mr O'Brien of the story, which may be apocryphal, that one of the country's most highly regarded authorities on wills and probate is said to have died intestate. The simple fact is that many people do not have time in their busy lives to take action in contemplation of serious illness or death however much they may intend to. Against Mr O'Brien's theory is a weight of evidence pointing towards what Mrs P would have wanted. At the conclusion of this case, though the Trust did not resile from its position, Mr O'Brien described the evidence relating to Mrs P's wishes as 'cogent, consistent and authentic'. Given that the Trust's own expert, Dr Walton, had said in evidence that if Mrs P's wishes were properly identified they should be determinative, it is difficult to see why the Trust did not review its position on evidence which they ultimately analysed as cogent. Logically and rationally it ought to have done. These cases

however, test people emotionally as well as intellectually and doctors and nurses are not exempt.

- 39. The Official Solicitor had remained neutral until the conclusion of the hearing when he acknowledged, through Mr Sachdeva, that there was clear and compelling evidence of Mrs P's wishes. Mr Sachdeva submitted and I agree that Mrs P's email gains significance when evaluated alongside the wider evidence of her wishes and feelings. In the light of this, the Official Solicitor I was told, now opposed the Trust's application. For the reasons I have set out above, I too have come to the conclusion that Mrs P would have found her present circumstances not only intolerable but humiliating. More than in any other sphere in her life she kept her health issues completely private. Her present high level of dependency and minimal awareness would, to her, have been 'a travesty of life', to adopt her own phase. Many other people have wholly different views; Mrs P is entitled to hers. Her incapacitous state does not mean her wishes can be disregarded. Her family, each of them, has permitted her voice to be heard and thus enabled her to assert her own autonomy. For the avoidance of any ambiguity I emphasise that I decline the Trust's application.
- 40. At one stage during the course of the hearing I wondered whether Mrs P would have been upset or disappointed that this case had come to Court and that different family members had taken opposing perspectives at various stages in the case. As I heard more about her, I began to think that this process was somehow strangely fitting. Mrs P loved a debate, they could be heated and she was undoubtedly headstrong. I think that she may very well have been proud of the way that her family have expressed themselves in the witness box. Each of them was respectful, reflective and had impressively structured their thought processes. Their love and affection for Mrs P is obvious.
- 41. I also heard from Mrs P's grandsons aged 14 and 12 years. They too were fine, impressive, articulate young men who told me their thoughts clearly and concisely. They spoke of a grandmother who had the ineffable 'coolness' of a different generation and whom they assessed as 'pretty good' with computer games. The younger of the two grandsons occupied himself at court making origami models. When I retired to consider this judgment, he handed one of his models to the usher to give to me. As a simple act of kindness for a judge about to take a very difficult decision it struck me as instinctively considerate and it was very much appreciated.
- 42. As medicine evolves, the law must keep pace. Each of these difficult cases presents a new, different and unique challenge. This case was heard in open court throughout because, in my assessment, the issues are of compelling public interest. Lawyers, doctors, judges and society generally learn something more with each case. Mr Sachdeva has invited me to give general guidance on a number of the issues that have arisen. I do not think the time has yet come to do so. However, what is clear from this case is that Mrs P was significantly discomforted by the NG tube and for a considerable period of time that may very well have been avoidable. Beyond that, I am prepared to say only this; cases in the Court of Protection must always be driven by the needs of the patient and not by the exigencies of the litigation. It is the responsibility of all involved to ensure that this is not lost sight of.