

Neutral Citation Number: [2019] EWCOP 18

Case No: 13398954

IN THE COURT OF PROTECTION

Preston Combined Court Centre Openshaw Place, Ringway Preston, PR1 2LL

Date: 22/05/2019

Before:

THE HONOURABLE MR JUSTICE MACDONALD

Between:

A Clinical Commissioning Group - and -P (By Her Litigation Friend the Official Solicitor) - and – TD Applicant <u>Applicant</u> <u>First</u> <u>Respondent</u>

<u>Second</u> <u>Respondent</u>

Mr Peter Mant (instructed by Hill Dickinson) for the The Applicant Mr Michael Horne QC (instructed by the Official Solicitor) for First Respondent The Second Respondent appeared in Person

Hearing dates: 13 May 2019

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.

.....

THE HONOURABLE MR JUSTICE MACDONALD

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 P, members of P's family and those caring for P 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 MacDonald:

INTRODUCTION

- 1. In this matter I am concerned with a decision of the utmost gravity in relation to P. Namely, whether this court should declare that P lacks capacity to make decisions regarding clinically assisted nutrition and hydration (hereafter CANH). In circumstances where the court concludes that P lacks capacity to decide for herself whether or not to continue to receive CANH, the applicant invites the court to consent on P's behalf to the withdrawal of that treatment, a step that will result in her death. In considering these applications, at all times P remains at the centre of the court's decision making process (see *Aintree University Hospitals NHS Trust v James* [2014] AC 591 per Baroness Hale).
- 2. The application is brought by a Clinical Commissioning Group. The applicant is responded to by the Official Solicitor acting as litigation friend for P and by TD, P's eldest daughter. Both the Official solicitor and TD support the application. Given the *very* limited geographical area covered by the CCG in this case, it is my intention to anonymise the identity of the CCG, and of the treating doctors in this case in order to avoid 'jigsaw' identification of P and her family.
- 3. In *An NHS Trust v Y* [2018] UKSC 46, the Supreme Court made clear that there is no requirement to go to court to seek approval for the withdrawal of CANH provided that (a) the provisions of the Mental Capacity Act 2005 have been followed, (b) the relevant guidance has been observed and (c) there is agreement as to what is in the best interests of the patient. However, where there is a disagreement as to a proposed course of action, or where the approach is finely balanced, an application to the court can and should be made.
- 4. In this case, as I have recounted, there is no dispute between applicant, the Official Solicitor and the family about the correct course of action. However, given certain contrary views expressed by the dedicated staff who now care for P and the neutral position taken by her treating clinicians in this case, the applicant made the decision to bring this matter before the court. Within this context, and whilst this application proceeds unopposed by all parties to it, I consider it appropriate to deliver a fully reasoned judgment given the particular circumstances of this case and the profound significance of the decision this court is now charged with taking.
- 5. In making my decision, I have had the benefit of reading the bundle lodged in this matter, which bundle includes the statements and attendance notes filed and served by the Official Solicitor, including a statement from James Beck of the Official Solicitor's Office exhibiting his attendance notes, dated 26 April 2019, a statement from David Edwards of the Official Solicitor's Office exhibiting his attendance notes, dated 9 May 2019, a statement from TD, dated 2 May 2019, a statement from NH, a Nurse Advisor, dated 15 December 2019 and the expert report of Dr Pinder, Consultant in Neurological Rehabilitation, dated 21 October 2018. I have also heard brief submissions from Mr Peter Mant, on behalf of the Applicant, Mr Michael Horne, Queen's Counsel, instructed by the Official Solicitor on behalf of P and from TD in person, and have had the benefit of both counsels' careful and considered Skeleton Arguments.

BACKGROUND AND EVIDENCE

- 6. In determining this matter, the Court must look at P's welfare in the widest sense, and accordingly examine not just the medical position but also P's social and psychological milieu. Within this context, and in circumstances where (a) the best interests test contains a strong element of substituted judgment that accepts that the preferences of the person concerned are an important component in deciding where her best interests lie, (b) both P's past and present wishes and feelings, and the beliefs and values (not limited to religious beliefs but also what was important to her, how that affected her view of the world) that would be likely to influence her decision are relevant and (c) the court must also look beyond those beliefs and values by considering any other factors that would have been likely to have influenced her in making the decision about whether to continue to receive CANH, it is important to consider the background in some detail.
- 7. In considering the background to this matter, I make clear that the descriptions of P set out below are those provided to the court by those who know her best.
- 8. P is an only child to her mother, HS. HS died in 2017. P however, has a half-sister, LD. P was raised in the North West, living until the age of eight with her mother and LD, at which point her mother moved out. It is clear from the evidence before the court that P and LD remained close thereafter. LD has attended this hearing.
- 9. P is described by those who know her as having been a "party girl", sociable and a person who loved dancing, singing and karaoke. She also loved talking to people and her family describe her, affectionately, as a person who was outgoing and enjoyed being the centre of attention. Within this context, her family describe her as someone who was the 'life and soul' of any party or family gathering. P is further described by her eldest daughter TD as having an adventurous spirit and TD recalls water fights in the garden, and her good cooking. TD also attends this hearing.
- 10. It is clear on the evidence from the family that is before the court that P cared about her appearance and was conscious about her weight, to a degree that created difficulties with her school attendance. She remained self-conscious regarding her appearance into adulthood. Her family note that she took care in her appearance until her downward spiral in the year before the drug overdose in April 2014 that led to the present position.
- 11. P was raised in the Catholic faith but stopped practising that religion in her late teenage years. As an adult, it would appear from the evidence that is available to the court that she had no religious beliefs. Her family relate that she did not talk about God. Within this context, I note that P expressed a very clear preference for a Humanist funeral without hymns both for her father and for herself.
- 12. As I have noted, P has an older daughter, TD. TD's father is NG. He too attends this hearing. In 2001 P and NG moved abroad, returning to this jurisdiction in 2003. They separated in December 2003. Following the separation NG states that their relationship was reasonable, although not always so, and they remained in contact. Following their separation, P and NG shared care of TD, with her spending weekends with NG and weeks with P. This arrangement changed in 2009, when TD went to live permanently with NG following P moving to a different town.

13. Thereafter, it is plain that P's life was not an easy one. The evidence before the court indicates that P commenced a relationship with a man who had overcome intravenous drug use. Tragically, he was seriously injured, suffering a traumatic brain injury that required him to be placed on life support. P was involved in the decision to terminate his life support. Her family consider that she found this upsetting. This sad event has taken on renewed significance in the context of these proceedings. At a best interests meeting concerning P held on 5 June 2014, her own mother, in commenting that P would not want to live in the circumstances that by then pertained also for her, provided details:

"... of her late partner who was on a life-support machine and P and his mother had to make the decision to turn off the life-support machine. P had said to her family that she would not want to be left in such condition if anything happened to her".

At that meeting, both HS and TD confirmed that that was the only conversation that they could recall having with P about this type of situation. However, as will be seen, each referenced P's statement in this regard on a number of occasions thereafter.

- 14. Following this difficult period, P entered another relationship, which association her family describe as "toxic", her then partner being a heavy drinker. He died of a methadone overdose in 2011 or 2012. During the course of that relationship, P had another daughter, S. P was described by her family of being incredibly proud of S and of idolising her youngest daughter. Following this difficult period, P moved once again, to be close to her own mother, HS. During this period she had contact with TD approximately three times per week. TD describes her and her mother as talking to each other more like friends than mother and daughter. TD considers that this period was the beginning of her mother's descent into drug and alcohol use.
- 15. The evidence before the court suggests that P began drinking to excess and taking illicit drugs in or around 2013. On 1 April 2014 P took an overdose of heroin. She was 42 years old. TD was 19 years old and S was 5 years old. As a result of her drug overdose, P suffered cardiorespiratory arrest and, in turn, a severe hypoxic brain injury. Initially, the diagnosis made by Dr H, a Consultant in Neurological Rehabilitation Medicine, on 23 May 2014 was one of a vegetative state. At best interests meetings held on 5 June 2014 and 16 June 2014, the clinical team concluded that it was too early to be sure whether P's condition would improve, although the prospects were considered to be very poor. Within this context, with respect to best interests decision making, during the course of this initial period following P's hypoxic brain injury, clinicians considered that it was premature to arrive at a longterm determination about her best interests in terms of continuing or withdrawing CANH. Having regard to the analysis this court is required now to undertake, and as I noted above, very early on P's own mother, HS, indicated at a best interests meeting on 5 June 2014 that P would not want to live in the circumstances in which she then found herself.
- 16. Following initial treatment at hospital, P was discharged to a nursing home (hereafter "the Unit") on 7 August 2014. The applicant continues to fund P's care at the Unit. Again, I note within the context this court is required to undertake, LC of the Unit recounts that both TD and HS told her that, when speaking about the decision to terminate the life support in respect of her then partner, P had said "... if it ever

happened to me I would not want to be a cabbage." Other staff recall HS saying that "this isn't P - P wouldn't want this."

- 17. It is important to note, for reasons that will become apparent, that the Unit is committed to rehabilitation work with those who suffer from neurological impairment. The home endeavours to improve the quality of life for all its residents, each of whom have very severe neurological disabilities. It is clear from the evidence before this court that the ethos of the Unit is about making the most of the lives of each individual labouring under neurological disability and endeavouring to maximise their potential. Within this context, a number of the staff at the Unit have made clear within the context of these proceedings that they have a strong 'pro-life' (their term) ethos.
- 18. Since her discharge from hospital into the care of the Unit, P has remained under the care of Dr H. P is tracheostomy-dependent, and tube-fed. Her tracheostomy requires regular suctioning. Initially, P was fed by way of a PEG tube. More recently, she has been fed via a nasogastric tube. P is completely immobile.
- 19. P's diagnosis has been the subject of some variation during the course of her period at the Unit. As I have noted, initially, the diagnosis made by Dr H on 23 May 2014 was one of a vegetative state. However, in December 2014, P was noted to display clear evidence of responses at greater than reflex level incompatible with a diagnosis of vegetative state, so the diagnosis was revised to that of minimally conscious state (hereafter MCS). Within the foregoing context, as Mr Horne QC for the Official Solicitor rightly submits, this court must recognise and engage with the fact that, over this period, there has been at times a difference of opinion as to P's level of awareness.
- 20. The faultline of this difference of opinion lies between the views of the Unit caring for P and the views of P's family, with the clinicians endeavouring to maintain a neutral position between these two poles. On 1 May 2015 a recording from the Unit indicates that "Clothes shopping; successful exercise; P was able to make a definite choice." At a best interests meeting on 27 May 2015, CR, the manager of the Unit, considered that P's communication was "Improving and becoming more reliable. P was using a mixture of eye closing, hand squeezing and eye contact. Her ability was variable and some days are better than others." Within this context, Dr H recorded in his clinic letter of that date that:

"Nursing staff report significant improvement in P's awareness and ability to communicate nonverbally and make choices such as which clothes she wants to buy and which activities she wants to participate in. However she remains severely disabled ..."

Dr H considered at this time that P might at some point be able to make her own choices about her care and that work needed to be done to improve her condition and to see whether she had capacity to make decisions.

21. Against this, neither HS nor TD had experienced the responses as set out above, although TD did agree that at that times she had seen her mother respond to music. In September 2015, Dr H noted that "Her family remain of the view that her wishes would have been for treatment to be withdrawn."

- 22. In terms of assessment, from September 2014 P underwent structured longitudinal assessment using the Wessex Head Injury Matrix ('WHIM'). Those assessments were completed by physiotherapists, speech and language therapists, and occupational therapists from the Acquired Brain Injury Team. The first assessment was on 19 September 2014, and the last was on 12 January 2016, less than 2 years after P's injury. There was no obvious trend towards improvement after 21 October 2014. The Official Solicitor understands that the relevant Acquired Brain Injury Team was then disbanded. Within this context, no further structured longitudinal testing was undertaken. I will deal with the issue of the absence of a longitudinal structured assessment beyond January 2016 below.
- 23. Dr H continued to review P's situation periodically. Following a review on 13 August 2017. He noted as follows in this context:

"... reviewed P ... And spoke to her daughter. Over the past 18 months or so, P has not been observed to make any meaningful responses to stimuli suggesting that she is now functioning at the vegetative rather than the minimally conscious level."...

Again in August 2017, following this reported period of no meaningful responses, Dr H further noted that:

"Her family are very clear that she would not want to live like this and are supportive of setting very clear ceiling to escalation of treatment and a palliative approach. ... They would also wish to explore the process of applying to the Court for withdrawal of feeding. ..."

24. The assessment of the staff at the Unit however, continued to be somewhat more optimistic. At a best interests meeting on 11 October 2017 the Unit's staff noted that P's progress had lapsed for the past 12 months but that she was showing signs of getting better again, with her reported as smiling, grimacing with pain and lifting her legs. Following the best interests meeting on that date, Dr H recorded that:

"I reviewed P and took part in the multidisciplinary best interest meeting. From descriptions of staff working closely with her, it is clear that P shows some responses which are incompatible with the diagnosis of vegetative state, giving her a diagnosis of minimally conscious state. ..."

Within this context, Dr H felt however that it was difficult to judge whether the responses could be reflex actions and stated that her condition was not going to improve and she was vulnerable to fitting, chest infections and future health complications. Cognitively, Dr H considered that P would not get any better. At the best interests meeting on 11 October 2017 TD again explained that P had told her, by reference to her former partner, that "... nobody should be left to live like that."

25. Dr H, and Dr N, P's general practitioner, declined to act as decision-makers in relation to the withdrawal of CANH. It is plain on the evidence before the court that this was a reasoned and reasonable position. On 9 May 2019, Dr H explained to the Official Solicitor's representative that he was only one of two Consultants in Neurological Rehabilitation in the area assessing patients at different stages of recovery from brain injury. Within this context, Dr H made clear that he adopted a

blanket policy of maintaining a neutral position and not expressing a view as to best interests, in order not to be categorised as someone who was either pushing for withdrawal or not. Within this context, I note that the joint *Royal College of Physicians and BMA Guidance on Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent* at page 23 does not oblige doctors in the position of Dr H to take on the role of decision-maker.

- 26. As I have noted above, there was opposition from the Unit to any discontinuation of CANH. The evidence before the court suggests that there were two linked reasons for that position. First, because the staff at the Unit considered that P felt pain, laughed, grimaced, and reacted, despite her all-encompassing dependence. Second, staff felt that any decision to discontinue CANH in relation to P could apply equally to all patients at the Unit. More generally, Ms PL (Clinical Lead at the Unit) told Dr Pinder that in stating that both she and her staff would not want CANH withdrawn, she stated that this was not particularly because they felt it was against the best interests, but because "... they are all 'pro-life' in general and do not agree with actively doing anything that is likely to shorten someone's life." Amongst the staff more widely, opposition to any withdrawal of CANH from P tended to involve general objections in principle to withdrawing CANH from a patient like P, a desire to continue caring for her and reluctance to be involved personally in the withdrawal, but also included opposition on the basis of the quality of P's life.
- 27. Within the foregoing context, and given the consistent and firmly expressed opinion of P's eldest daughter, TD, half-sister, LD, and former partner, NG in favour of the withdrawal of CANH, the applicant agreed to take the lead in considering invoking the legal process to obtain a decision on whether it was in P's best interests for CANH to be withdrawn.
- 28. As I have noted, as part of that consideration, the applicant instructed Dr Pinder, Consultant in Neurological Rehabilitation, to assess P and to provide an independent second opinion on her condition. Dr Pinder attended the Unit on 12 October 2018 to see P, spoke to NG and TD and, as I have already noted, also discussed P with Ms PL.
- 29. Dr Pinder's investigations reflected the continuing difference of view between the family and the Unit as to P's presentation and levels of awareness. TD told Dr Pinder at the time of his assessment that P never had any response, she never made eye contact, and that she had "nothing now". She did not describe any change when S visited her mother. By contrast, at the time of his assessment, Ms PL, Clinical Lead, told Dr Pinder that:

"P does not give any eye contact and all communication has to be based on facial expression. Ever seems to smile if she is enjoying something such as gentle tactile approach during personal care or pampering, or when the sensory lights are on. She does move her feet when given foot spa. On one occasion she appeared to smirk in response to a joke. There does not appear to be any consistent differences in behaviour when treated by different members of staff. ... She goes out of the nursing home to the shops or to [the] beach. On trips out she does seem to be more awake or alert but they are unable to tell whether there is any indication that she is any more aware of her surroundings."

30. It is clear from the attendance notes exhibited to the statement of James Beck that most of the staff who care for P consider that she exhibits signs of awareness, particularly when taken out of the care home. These are said predominantly to be smiling, giggling and laughing. For example, staff recalled that on 15 December 2018:

"Whilst the Christmas party at the Unit ... P had some funny Xmas bands on her face & head, I was stating how funny we both looked and as a response P gave myself lots of smiles and laughs..."

Staff further recalled that on 29 January 2019:

"... I said to her I will get you to smile at me one day P, I was watching the TV straight after having the conversation, then I turned around fast and said Boo, P then gave me a big smile"

There is however a concession that these signs are not consistent, and that there are long periods when P shows no signs of alertness and appears to be sleeping even when her environment is noisy. When interviewed by Mr Beck on 12 April 2019, TD did not dismiss the reports that P was said to smile, but explained that her mother mostly appeared to be asleep when she visited and considered that other behaviours were just reflexes.

- 31. When Dr Pinder conducted his examination of P he considered that she had very little, if any spontaneous movement. He assessed her eye movements as roving and dysconjugate. Dr Pinder noted a very brief fixation himself for a family photograph, but only for one or two seconds. P did not follow a picture of her daughter with her eyes or head. In addition Dr Pinder found no localisation to movement of sound, no response to voice or command and no localisation to pain.
- 32. Dr Pinder produced his report on 21 October 2018. Prior to the completion of his report, Dr Pinder had not considered the extensive notes from the Unit, in which notes, as I have outlined, are recorded a range of behaviours from P. The Official Solicitor therefore asked Dr Pinder to consider the key sections of those notes, which sections deal with psychological behaviour and social activity from 2014 to date and record multidisciplinary liaison, psychological and behavioural changes, social activities and correspondence.
- 33. Having undertaken this exercise, the overall conclusions of Dr Pinder, taking into account his assessment of P, his conversations with family and carers and his review of the extensive notes at the Unit, can be summarised as follows:
 - i) During assessment on 12 October 2018 there was no response from P that could be interpreted consistently as being above the level of reflex. P has shown some behaviours that appear, at face value, to be inconsistent with being reflex behaviours. The frequency with which these behaviours occur varies widely and according to the behavioural charts can be very infrequent at times.
 - ii) Whilst it has previously been reported that P displayed some response to command by blinking, apparently moving her tongue and squeezing fingers,

this again has not been consistent. A proportion of P's blinking will have represented an active response to command rather than reflex. The frequency of this behaviour was recorded to be at its peak in the middle of 2016, but even then only once every four to seven days. This behaviour does not constitute a reliable method of communication and it has not been possible to develop a consistent system of communication with P utilising these apparent responses.

- iii) P's awareness of the world around her will be very limited and there are long periods where she has no awareness at all. P will have "islands of time" where her level of awareness is better, but this will vary from being alert but unaware, to being able to make very basic binary choices for short periods of time, such as which of two items she would like to be placed where.
- P's cognition will be slightly better when she is not fatigued, not otherwise unwell, not overstimulated, not influenced by medication and not low in mood.
 When all of those factors are optimal P will show some slightly higher levels of awareness and responsiveness to the extent that she may be able to interpret tone of voice or perhaps one or two words said to her.
- v) It is not possible to determine from the behaviour charts and notes the frequency and duration of the periods of increased awareness, but these periods seem to have become much less frequent after the middle of 2016. Even when maximally aware, P will have very little insight into her condition and, to the extent she is aware, is likely to be significantly depressed in the context of her situation.
- vi) All of P's sensory input will be disordered. She can see, but it is impossible to determine the degree to which she is able to understand what she is seeing and her understanding of visual input is likely to be limited. She can hear, but it is impossible to know what she is able to understand. P is said to perceive touch but any response was not sufficient for Dr Pinder to record. She will not experience smells because of her tracheostomy, and she will not experience taste, because she is tube-fed.
- vii) P has no significant functional movement, other than, possibly, an unreliable control of her eyelids.
- viii) It is not possible to determine whether P is experiencing pleasure or enjoyment. The only behaviours documented that may indicate this is her smiling or appearing relaxed. It is however, very difficult to determine whether this is a reflex behaviour, or whether it is an active movement to indicate happiness. Within this context, Dr Pinder has carefully analysed a short video clip sent to the Official Solicitor by staff the Unit, which is said to show the episode of P laughing at the Easter party this year as described above. Dr Pinder agrees that the response P shows in the video can be interpreted as her 'laughing'. However, having considered each step in the video, Dr Pinder is also clear that this is a reflexive response to being kissed rather than a display of awareness of humour.
- ix) It is not possible to determine, from P's records, how frequently she appears to be experiencing pain or discomfort. She often appears unsettled when she has

an increase in the amount of secretions from her chest, which settles when she has been given paracetamol. At other times she is given pain relief, but this seems to be prior to activities, such as changing the dressing on her PEG, which were expected by staff to be painful.

- x) P does not seem to behave differently with any particular members of staff or her family and she does not appear to differentiate between people she knows and people she does not know. There was no consistent evidence that P gained more or less pleasure being in the presence of her family than in the presence of others. She is unable to form any positive or negative meaningful relationships with others.
- xi) A further structured assessment will not give further useful information as to P's level of awareness, enjoyment of life or whether she experiences pain or discomfort.
- xii) The responses in the behaviour charts from the Unit are not inconsistent with a diagnosis of MCS. On the basis of the assessment and the observations of the community neurological rehabilitation team P is in a minimally conscious state;
- xiii) P's life expectancy is limited to four to six years from 2018.
- 34. Within the foregoing context, P's clinicians maintained their position of neutrality and the Unit maintained its expressed reservations with respect to the removal of CANH. At a best interest meeting on 3 January 2019, TD, LD and NG maintained their position that P would not have wanted to live as she is. Within this context, the applicant took the decision to proceed with this application in the Court of Protection.
- 35. Within these proceedings, and ahead of this final hearing, the Official Solicitor has conducted extensive investigations pursuant to directions made by this court on 22 February 2019. In particular, as alluded to at points in this judgment, the Official Solicitor, acting on behalf of P, has:
 - i) Obtained disclosure of, and reviewed the relevant clinical records pertaining to P;
 - ii) Raised two sets of further written questions of the expert in this matter, Dr Pinder, to which Dr Pinder has responded in full;
 - James Beck, of the Official Solicitors Office, visited the unit caring for P on 1 April 2019 and twice on 8 April 2019 to interview members of staff, both in person and over the telephone;
 - iv) James Beck has spoken to the family of P and David Edwards of the Official Solicitors Office has followed-up those conversations in light of Dr Pinder's responses to the Official Solicitor's further questions.
 - v) David Edwards has spoken to Dr H and again to family members in light of Dr Pinder's responses to those questions.

36. Mr Beck has in particular explored further with TD and LD the conversation they had with P in the context of her involvement in the decision to terminate the life support of her former partner. TD related to Mr Beck that:

"... there was a choice between letting R die or letting him live a life where he could couldn't do anything, where he could not walk and couldn't talk. P told TD that she wouldn't leave someone like that and she wouldn't do that to a dog"

This recollection was consistent with that of LD, who remembered that P had said she would not:

"let a dog live like that ... they both had agreed that they wouldn't want to be left living like R would have been had treatment not been withdrawn. Both of them had said that they would not leave the other living like that. They also shared these views with their other cousins and they all agreed that it wouldn't be fair to leave someone living like that."

37. The Official Solicitor has also explored further the family's views regarding the continuation of life sustaining treatment for P. As I have noted, P's mother, HS, made some clear statements to staff prior to her own death in 2017, including that "this isn't P - P wouldn't want this." Staff at the Unit have suggested that HS's views may have changed over time, PL reporting that:

"HS seemed glad treatment had not in fact been withdrawn. She made comments about this on several occasions. [Staff] had many in-depth conversations with HS during the last 18 months of life and she appeared to remain of the view that P's care and treatment should continue".

However, whilst agreeing that HS became more accepting of treatment, other staff were not sure that she had actually changed her mind about its withdrawal. Both TD and LD consider that HS did not change her mind. TD stated that during the last year of her life HS would say things like "I saw your mum it is awful to see [her] like that". LD goes further, telling Mr Beck that it is her belief that if HS had known that she was going to die so soon, she would have taken P with her in a mercy killing. This information is also verified by TD in her statement. Both suggest that the Unit were aware of this and implemented a safety plan that ensured that HS was alone with P for the last year of her life. There is no independent corroboration of this assertion before the court.

38. The evidence before the court, including the account of the investigations undertaken by the Official Solicitor, indicates that TD has been entirely consistent in her view that her mother is not the person she was and that P herself would not want to live in her current condition through the continuation of life sustaining treatment. TD has placed consistent reliance upon P's actions and reaction to the withdrawal of treatment from her former partner as evidence of what P herself would have wanted. I also note, within the context of the evidence before the court that P was extremely conscious of her appearance during her lifetime, that Ms CR reports that TD was initially unhappy to find that the Unit took her mother out as she did not like people seeing her mother in the condition she was, TD explaining that: "... if her mum knew what was going on she would be mortified and would consider it undignified because P was someone who cared about her appearance and would not want others to see her the way she is now."

Within this context, it was clear from the brief submission that she made to the court that TD now sees an unbridgeable gulf lying between the mother she knew prior to April 2014 and the situation she now sees when she visits P. TD told me that her mother is "not a person anymore" and that "I know she would not have wanted this".

39. LD has likewise not wavered in her belief that P herself would want CANH withdrawn. LD now cares for P's younger daughter, S. A clear factor in LD's thinking is the belief that P would not have wanted the current situation to be impacting upon S in the way it is. LD reports that S appears to have found visits to her mother increasingly upsetting and an ordeal. Within this context, LD reports that, for the last two years, S has not wanted to go as it makes her sad. Within this context, LD states that:

"... as things are she doesn't feel that S is able to properly enjoy life. S seems to feel she's betraying P by showing affection and love to others. She refers to LD's husband has her "dad" and will refer to LD as her "mum" but at times she appears to feel guilty about calling LD her mum and will say that P is her mother. LD feels that the current situation is stopping S from moving on with her life. She described it as not a normal situation. S is going to high school in September and LD feel she needs a fresh start".

LD considers that P would not have wanted S to experience these emotions. Given her age, S has not been asked her views. It is apparent from the evidence before me that that she keeps saying that she wants her mum back to cuddle, to take her to the park, to tell her things; she wants her old mum back.

- 40. The evidence before this court indicated that once CANH is withdrawn from P it is likely that a period of a few days will pass before P dies. Within this context, P's death would be managed with the aim of seeking to ensure her end is dignified, in an environment where she could be given appropriate palliative care with the aim of preventing any discomfort during the process. Dr Pinder's report makes clear however, that it is impossible to exclude the chance that, notwithstanding such measures, P could suffer some discomfort.
- 41. Within this context, it is unfortunate that the applicant has not provided the Official Solicitor and the court with an end of life care plan outlining in detail the steps that will occur if the Court authorises the withdrawal of CANH. This situation arises within the context of the staff at the Unit not wishing to engage in a planning process until the outcome of this hearing is known and they have had a chance to consider whether they would be prepared to offer end of life care to P in the event the court authorised withdrawal of treatment. In the circumstances, if permission is granted for that course of action to be taken, P will need to be moved from the Unit (although it would appear that there are some staff who consider that if CANH is to be removed they would wish to care for P in her final days). Given P's limited awareness of her surroundings, the move to new surroundings is unlikely to be a significant detriment to her. Within this context, no end of life care plan has yet been compiled and the court is accordingly invited by the parties to make an 'in principle' decision with

permission to the parties to apply in the event of any disagreement over the care plan arrived at.

RELEVANT LAW

Capacity

42. The law that I must apply to the facts in this case in reaching my decision as to P's capacity is set out in the Mental Capacity Act 2005 ss. 1 to 3. The sections of the Act relevant to my decision provide as follows:

1 The principles

(1) The following principles apply for the purposes of this Act.

(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

(4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

.../

2 People who lack capacity

(1) 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.

(2) It does not matter whether the impairment or disturbance is permanent or temporary.

(3) A lack of capacity cannot be established merely by reference to-

(a) a 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 his capacity.

(4) In proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.

.../

3 Inability to make decisions

(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate his decision (whether by talking, using sign language or any other means).

(2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).

(3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

(4) The information relevant to a decision includes information about the reasonably foreseeable consequences of—

(a) deciding one way or another, or

- (b) failing to make the decision.
- 43. The cardinal principles that flow from these sections of the statute can be summarised as follows:
 - i) A person must be assumed to have capacity unless it is established that they lack capacity (Mental Capacity Act 2005 s 1(2)). The burden of proof lies on the person asserting a lack of capacity and the standard of proof is the balance of probabilities (Mental Capacity Act 2005 s 2(4) and see *KK v STC and Others* [2012] EWHC 2136 (COP) at [18]);
 - Determination of capacity under Part I of the Mental Capacity Act 2005 is always 'decision specific' having regard to the clear structure provided by sections 1 to 3 of the Act (see *PC v City of York Council* [2014] 2 WLR 1 at [35]). Thus capacity is required to be assessed in relation to the specific decision at the time the decision needs to be made and not to a person's capacity to make decisions generally;
 - iii) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (Mental Capacity Act 2005 s 1(3));
 - A person is not to be treated as unable to make a decision merely because he or she makes a decision that is unwise (see *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP) at [7]). The outcome of the decision made is not relevant to the question of whether the person taking the decision has capacity for the purposes of the Mental Capacity Act 2005 (see *R v Cooper* [2009] 1 WLR 1786 at [13] and *York City Council v C* [2014] 2 WLR 1 at [53] and [54]);
 - v) Pursuant to s 2(1) of the 2005 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 (the so called 'diagnostic test'). It does not matter whether the impairment or disturbance in the functioning of the mind or brain is permanent or temporary (Mental Capacity Act 2005 s 2(2)). It is important to note that the question for the court is not whether the person's

ability to take the decision is *impaired* by the impairment of, or disturbance in the functioning of, the mind or brain but rather whether the person is rendered *unable* to make the decision by reason thereof (see *Re SB (A Patient: Capacity to Consent to Termination)* [2013] EWHC 1417 (COP) at [38]);

- vi) Pursuant to s 3(1) of the 2005 Act a person is "unable to make a decision for himself" if he is unable (a) to understand the information relevant to decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate his decision whether by talking, using sign language or any other means (the so called 'functional test'). An inability to undertake any one of these four aspects of the decision making process set out in s 3(1) of the 2005 Act will be sufficient for a finding of incapacity provided the inability is because of an impairment of, or a disturbance in the functioning of, the mind or brain (see *RT and LT v A Local Authority* [2010] EWHC 1910 (Fam) at [40]). The information relevant to the decision includes information about the reasonably foreseeable consequences of deciding one way or another (Mental Capacity Act 2005 s 3(4)(a));
- vii) For a person to be found to lack capacity there must be a causal connection between being unable to make a decision by reason of one or more of the functional elements set out in s 3(1) of the Act and the diagnostic element of 'impairment of, or a disturbance in the functioning of, the mind or brain' required by s 2(1) of the Act, i.e. for a person to lack capacity the former must result from the latter (*York City Council v C* [2014] 2 WLR 1 at [58] and [59]);
- viii) The threshold for demonstrating capacity is not an unduly high one (see *CC v KK & STCC* [2012] EWHC 2136 (COP) at [69]).

Best Interests

44. The Mental Capacity Act 2005 s 4(1) provides as follows in respect of determining the question of best interests:

4 Best interests

(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.
- 45. In order to determine the question of best interests the court must consider all the circumstances of the case (Mental Capacity Act 2005 s 4(2)). The assessment of best interests under the Mental Capacity Act 2005 s. 4 is thus an assessment wide in compass and not confined to an assessment only of the best medical interests of the patient. Beyond this description however, it has been observed that it is undesirable, and probably impossible, to set bounds on what matters will be relevant to a welfare determination (Re S (Adult Patient: Sterilisation) [2001] Fam 15 at 30). As Hedley J noted in Portsmouth NHS Trust v Wyatt [2005] 1 FLR 21 "the infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests." In Aintree University Hospitals NHS Foundation Trust v James & Ors [2014] AC 591 at [24] Baroness Hale noted that s.4 of the 2005 Act does not propose a totally objective best interests decision making process but contains a "strong element of substituted judgment" which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie. At [39], noting that the purpose of the best interests test is to consider matters from the patient's point of view, Baroness Hale further observed that:

"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 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."

- 46. In considering all of the circumstances of the case in order to reach a best interests determination, the 2005 Act requires the court to consider a number of specific matters:
 - i) Whether it is likely that the person will at some time have capacity in relation to the matter in question and, if it appears likely that they will, when that is likely to be (Mental Capacity Act 2005 s. 4(3)). The MCA Code of Practice at para 3.14 provides that where a person's capacity is likely to improve in the foreseeable future then, if practical and appropriate, the person should be helped to make the relevant decision by waiting until their capacity improves. The Code of Practice at para 4.27 provides that an assessment must only examine a person's capacity to make a particular decision when it needs to be made and, accordingly, it may be possible to put off the decision until the person has capacity to make it. However, para 5.26 of the Code of Practice recognises that in emergency situations, such as when urgent medical treatment is needs, it may not be possible to see if the person may regain

capacity so that they can decide for themselves whether or not to have the urgent treatment;

- The person's past and present wishes and feelings (and, in particular, any ii) relevant written statement made by them when they had capacity) (Mental Capacity Act 2005 s 4(6)(a)). The Court must inquire into and then consider all evidence of wishes and feelings before taking the decision (see paragraphs 5.18 to 5.20 of the MCA Code of Practice). Other evidence may include evidence from relatives and those who have cared for her about her wishes and feelings which may assist the Court to understand P as a person. It is important to be rigorous and scrupulous in seeking out what P's views would have been about the decisions in issue. Their clarity, cogency and force will have a direct impact on the weight they are to be given (see *Sheffield Teaching* Hospitals NHS Foundation Trust v TH [2014] EWCOP 4 at [56]). If her present wishes can be ascertained with reasonable confidence, they should not be undervalued (see Wye Valley NHS Trust v B [2015] EWCOP 60 at [10] to [18]).
- The beliefs and values that would be likely to influence their decision if they had capacity (Mental Capacity Act 2005 s 4(6)(b)). This includes not just religious beliefs but what was important to P, how that affected her view of the world and the factors which P thought were important in taking decisions for herself;
- iv) The other factors that P would be likely to consider if she were able to do so (Mental Capacity Act 2005 s 4(6)(c));
- v) If practicable and appropriate, the views of, *inter alia*, anyone named by the person as some to be consulted on the matter in question, anyone engaged in caring for the person or interested in her welfare as to what would be in the person's best interests and in particular as to the matters set out in s 4(6) of the 2005 Act (Mental Capacity Act 2005 s 4(7)).
- 47. The court must also, so far as reasonably practicable, permit and encourage P to participate, or to improve her ability to participate, as fully as possible in any decision affecting her (Mental Capacity Act 2005 s. 4(4)).
- 48. In assessing whether it is a patient's best interests to receive treatment that will or may prolong her life, the fundamental principle of the sanctity of human life will weigh heavily in the balance, having its origins as it does in "a profound respect for the sanctity of human life is embedded in our law and our moral philosophy" (see *Airedale NHS Trust v Bland* [1993] AC 789 at 808). The MCA Code of Practice, to which the Court must have regard, makes it clear that "all reasonable steps which are in the person's best interests should be taken to prolong their life", and that there will only be "a limited number of cases" where that should be displaced.
- 49. However, the presumption in favour of the sanctity of life is not absolute. Within the particular context of this case, one of the considerations relevant to the question of the weight to be attached sanctity of life in the court's analysis is what P herself would have thought of this issue in the circumstances of the case (see *Airedale NHS Trust v Bland* at 863 and *M v Mrs N & Others* [2015] EWCOP 76 at [32]). In *In re Briggs*

(*Incapacitated Person*)(*Medical Treatment: Best Interests Decision*) (*No.2*) [2017] 4 WLR at [62] Charles J observed as follows regarding the interrelationship between the presumption in favour of the sanctity of life and P's wishes and feelings on an intensely personal issue where the same are ascertained with sufficient certainty:

"[62] ... when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes: i) the decision maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want, and ii) 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."

And at [71]:

"[71] I acknowledge and urge that the evidence and reasoning relied on to reach a conclusion that P would not have given consent to the relevant lifesustaining treatment, and then to rely on it as a weighty or determinative factor to depart from the default position that P's best interests are promoted by preserving his or her life, requires close and detailed analysis which founds a compelling and cogent case that this is what the particular P would have wanted and decided and so considered to be in his or her best interests."

50. Within this context, in M v N at [32] Hayden J observed as follows regarding the interrelationship between the sanctity of life and cogently expressed wishes:

"...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 that those of the capacitous".

51. Human dignity is also relevant when considering the weight to be placed on the sanctity of life. As Munby J (as he then was) observed in *R* (*Burke*) v *GMC* [2004] EWHC 1879 (Admin) in a passage approved by the Court of Appeal:

"There is a very strong presumption in favour of taking all steps to prolong life and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In case of doubt, that doubt falls to be resolved in favour of the preservation of life. But the obligation is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity..."

52. Pursuant to the Mental Capacity Act 2005 s 4(1) the decision as to what is in a person's best interests must not be taken merely on the basis of the person's age or appearance nor on the basis of the person's condition, an aspect of their behaviour

that might lead others to make unjustified assumptions about what might be in the person's best interests.

- 53. Within this context it is also important to remember that, by reason of the inalienable and universal character of human rights, a person who lacks capacity has the same human rights as a person who does not lack capacity (see *P v Cheshire West* [2014] UKSC). In addition to rights under Art 2 of the ECHR, P benefits from rights under Art 3 (right not to be subjected to torture or to inhuman or degrading treatment or punishment) and Art 8 (right to respect for family and private life) under the Convention. The assessment of P's best interests must take account of these rights.
- 54. There is no prohibition on conducting a best interests analysis with respect to the continued provision of CANH even though P is not in a vegetative state (see *W v M* [2011] EWHC 2443 (Fam) at [102] and *Salford Royal NHS Foundation Trust v Mrs P* and Anor [2017] EWCOP 23).

DISCUSSION

- 55. As I announced at the conclusion of the hearing, and with profound sadness, I am satisfied that P lacks capacity to make decisions about her medical treatment, and specifically about the withdrawal of CANH. I am also satisfied that she lacks capacity to conduct these proceedings. Further, I am satisfied that it is in P's best interests for CANH to be withdrawn once an end of life care plan has been agreed and approved by the court. Within this context, I am satisfied that, having determined that continued CANH is not in P's best interests, and upon an end of life care plan being agreed and approved by the court, on behalf of P the could should withhold its consent for ongoing CANH. My reasons for reaching this grave decision are as follows.
- 56. On the evidence before the court, I am satisfied on the balance of probabilities that P now exists in a minimally conscious state. Both Dr H and Dr Pinder conclude that this is the appropriate diagnosis. The Official Solicitor accepts that P is in MCS. There is no evidence before the court to gainsay this diagnosis. Whilst Dr H categorises P as being in a "a low level minimally conscious state", Dr Pinder does not further differentiae his diagnosis. Within this context, I note that at page 7 the Royal College of Physicians' *Prolonged disorders of consciousness: National Clinical Guidelines* (2013) does not regard formal sub-categorisation of MCS as helpful. However, it is nonetheless important in this case that the court engage with the evidence, summarised above, that has driven the marked difference of opinion between the family and those who look after P on a day to day basis.
- 57. As demonstrated above, there has been a mismatch between the perception of many of the staff at the Unit and P's family as to her level of awareness and response. As Mr Horne points out, differences in perception of awareness and responsiveness in a patient with a prolonged disorder of consciousness between family members and care staff at a nursing home are not at all uncommon. It is likewise important that the evidence of care staff as to the existence of behaviours should be given due consideration in circumstances where they, ordinarily, spend more time with a patient than do family members. Against this however, the question for the court is not whether those behaviours are displayed, but rather whether any such behaviours denote a level of awareness or are merely reflex in nature. In this latter context,

expert evidence will be important. Whilst in reaching its decision, the court must take into account all the circumstances of the case, I agree with Mr Horne that, as Consultants in Neurological Rehabilitation, Dr H and Dr Pinder are best qualified to interpret the significance of P's inconsistent and limited responses.

- 58. As set out above, Dr Pinder has undertaken a comprehensive assessment of P, including consideration of the relevant records from the Unit in which the behaviour witnessed by those caring for her has been recorded. Within this context, Dr Pinder considers that there is no response from P that could be interpreted consistently as being above the level of reflex and, having regard to her responses, P's awareness of the world around her will be very limited with long periods where she has no awareness at all. Dr Pinder is clear that P's sensory input will be disordered, that she has no significant functional movement and that it is not possible to determine experience of pleasure or pain. There is nothing in the evidence with respect to Dr H's views that calls these conclusions into question. Whilst I have borne in mind the observations of the staff at the Unit, having regard to the nature and extent of his assessment of P should be accepted by the court and I do so. As I have noted, that assessment clearly identifies that P is in MCS.
- 59. Within the foregoing context, I am mindful in this case, and have borne carefully in mind, that the court does not have the benefit of an up to date longitudinal functional assessment. This is unfortunate for a number of reasons. First, the joint Royal College of Physicians and BMA Guidance *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent* (2017) states that it is essential that patients in a vegetative state or MCS after brain injury undergo a thorough, expert assessment in accordance with the Royal College of Physician's *National clinical guidelines on Prolonged Disorders of Consciousness* (2013). Second, the RCP's 2013 PDOC Guidelines state that formal structural assessments should be undertaken three to five years after the onset of brain injury. Third, in this case, the last of the twenty-four WHIM assessments undertaken by the Community Brain Injury Rehabilitation team was on 12 January 2016, less than two years after P's injury.
- 60. In circumstances where a central part of the purpose of longitudinal functional assessment is to inform prognosis by providing detailed evidence of the trajectory of the patient's clinical course, the Official Solicitor submits that this omission is regrettable. Against this however, the Official Solicitor submits that Dr Pinder is clear in his opinion that a further longitudinal functional assessment is not likely to give any further information that would lead to an alternative diagnosis, or as to P's current level of awareness, enjoyment of life or whether she experiences pain or discomfort. In addition, the Official Solicitor points to the fact that the detailed notes from the Unit do not suggest any improvement of significance in the last two years. In this context, I note that at the best interests meeting of 11 October 2017, Dr H concluded that P's "condition is not going to improve; she is vulnerable to fits, chest infections and potential future health complications and cognitively won't get any better." Further, when Dr Pinder undertook his own WHIM assessment on 12 October 2018, P displayed only five behaviours, the most advanced of which was looking at a person briefly. That score is considerably below the score of twenty-six on various occasions in 2015 and 2016. Finally, when pressed by the Official Solicitor to provide an estimate of the 'best realistic case' for P, in his letter of 30 April 2019 Dr Pinder

describes the prospects of any significant improvement as "negligible". In the circumstances, I am satisfied that it is not necessary for the court to order further longitudinal assessment before determining this matter.

- 61. Within the foregoing context, Dr Pinder and Dr H, consider that P has an "impairment of, or a disturbance in the functioning of, the mind or brain" within the meaning of s.2 MCA. The Official Solicitor accepts that evidence and there is no evidence before the court that contradicts this conclusion. Further, both Dr H and Dr Pinder agree that in her MCS P is "unable" within the meaning of ss.2 and 3 of the 2005 Act to decide whether to continue receiving CANH. They also agree that there is no prospect of P recovering that capacity. Once again, the Official Solicitor accepts that evidence and the court has no evidence before it that contradicts that view.
- 62. With respect to P's best interests, the Official Solicitor submits that P's past wishes and feelings on such an intensely personal issue as whether her CANH should be withdrawn can be ascertained with sufficient certainty and, on the particular facts of this application, should prevail over the very strong presumption in favour of preserving her life where those wishes were clearly against being kept alive in her current situation. Dr Pinder likewise considers that the overriding factor in the best interests assessment is her previously expressed wish that she would not want to live in her current condition. I agree for the following reasons.
- 63. P did not compile an advance directive, nor any other written document setting out her wishes in the present circumstances. However, having regard to the matters set out above, I am satisfied that when speaking of the termination of her former partner's life support P did make clear that she would not want to be left in such a condition if anything happened to her and that she commented that "if it ever happened to me I would not want to be a cabbage." I am also satisfied that P told TD that "she wouldn't leave someone like that and she wouldn't do that to a dog". As well as repeating this view to LD, in speaking to LD and her other cousins, I accept that P participated in a conversation in which they all agreed that it wouldn't be fair to leave someone living "like that." The evidence about P's statements when confronted with the stark consequences of her former partner's catastrophic brain injury is broadly consistent as between TD and LD. No one seeks to gainsay the evidence of TD or LD on this point.
- 64. In terms of strength with which P's views were expressed, I have further had regard to the fact that, within the context of HS and TD being told whilst P was still an inpatient that there was a 99% chance that she would either die without improving, stay the way she was or improve slightly to a state which was one step up from a vegetative state, P's previously stated views were relayed to treating clinicians very soon after April 2014. As I have noted, HS raised P's views as early as the first best interests meeting on 5 June 2014, and those views have been repeated outside of formal meetings to staff members. In this respect, I have also had regard to the fact that these statements were made by P in the face of a similar situation that had befallen a loved one. P's wishes in this regard were expressed in circumstances where she was said to have been involved in making a decision about whether her former partner should be allowed to die or live in a situation similar (although not identical) to that in which she now finds herself.
- 65. Within this context, and having regard to the matters set out above, I am satisfied on the balance of probabilities that prior to becoming incapacitated, P expressed a clear

and firmly held view that she would not want to be kept alive in circumstances in which she now finds herself.

- 66. In addition, the evidence with regard to P's character and outlook on life generally is consistent with the clear views I am satisfied she expressed about being kept alive in the circumstances she is currently in. As I have noted above, P is described as having been 'life and soul' of every family event and conscious of her appearance and presentation. Whilst raised in the Catholic faith she did not practice that religion as an adult. These matters further reinforce my conclusions as to the nature and strength of P's expressed views regarding being kept alive in a moribund state. I am further satisfied within this context that the court can properly infer that the loss of the ability to communicate, to socialise, to sing and dance, or to return to her active vivacious self, would all have had a profound negative impact upon P and would have informed her decision making on the issue now before the court.
- 67. I am also satisfied that, having regard to the evidence as to the care and pride she took in S, that it is unlikely that P would have wished S to have to bear the emotional consequences of her remaining in a minimally conscious state for what is to assessed to be the remainder of her short lifespan, and that this too would have informed P's decision making. Permitting S to move on with her life rather than to experience the upset of repeated visits over the next three to five years would, I am satisfied, have been an important additional factor in any decision P made about continuing CANH. With respect to P's *present* wishes and feelings, I accept the submission of Mr Horne that no reliable inference can be drawn from what may be signs of pleasure or pain as to whether P has any present wishes about the continuation of CANH, let alone the nature of her views.
- 68. I have also paid close regard to the views expressed by P's older daughter, TD and her half-sister, LD. I am satisfied that those expressed views, as summarised above, are consistent with, and reinforced by what they each knew and understood of the wishes expressed by P in this context. It is also significant in this regard that the views of HS (when alive), TD and LD are, I am satisfied, unanimous in their conclusion that CANH should not be continued in circumstances where I am equally satisfied that the motivation for their views is overwhelmingly that which P herself expressed as wanting in this situation. A further strong theme in the family's own views on this application is that because of her character and values, P herself would have rejected the continuation of CANH. I am satisfied that this is reflective of their understanding of what P believed and who she was before she lost capacity.
- 69. I have also given careful consideration to the views of the staff of the home in which P is cared for. They have the advantage of regular contact with P and are in a position to develop a detailed picture of her current presentation. Against this, they have not had the benefit that the family have had of knowing P when she was capacitous and of seeing and experiencing all of the many varied facets of her character, what she thought, what was dear to her, what she wished for the future and, importantly, what she believed about the situation in which she now finds herself. Whilst the 'pro-life' approach (as they themselves describe it) taken by a number of the members of staff in the current situation is a valid point of view, in the circumstances of this case I am satisfied that it is contrary to the clearly expressed view of P before she lost capacity.

- 70. I have paid solemn regard to the principle of the sanctity of life. P's life is, as all lives are, uniquely valuable and is a life that is valuable in a number of different contexts. It is plainly valuable to her family, it is precious to those who now care for her and it is also important for the way in which it adds to the body of collected human experience. However, as I have noted above, the principle of the sanctity of life is not an absolute one.
- 71. As Charles J made clear in *In re Briggs (Incapacitated Person)(Medical Treatment: Best Interests Decision) (No.2)* at [71], and as Hayden J made clear in M v N at [32], the wishes and feelings of an incapacitated adult, ascertained with sufficient certainty through their cogent and authentic communication to the court via family or friends, can found a compelling and cogent case as to what P would have wanted and would have decided in respect to the decision under consideration. Where P's wishes can be ascertained with sufficient certainty in this way, they should generally prevail over the very strong presumption in favour of preserving life. I am satisfied that the evidence set out above founds a compelling and cogent case that P expressed a clear view that she would not wish to be kept alive in the circumstances in which she now finds herself.
- 72. Within this context, in this case I am satisfied that the presumption in favour of life should give way to what I am content were P's strongly held views prior to her becoming incapacitated that she would not wish to be kept alive in her current parlous condition. That view is, I am satisfied, established with sufficient certainty. Indeed, in the context of the undisputed recollections of TD and LD, as I have said, I am satisfied that there is a compelling and cogent case that P would not have wanted to live in her current situation and made the same clear.
- 73. I am also satisfied that P's dignity must be balanced against the principle of the sanctity of life. Having regard to the prognosis provided by Dr Pinder, I am satisfied that if CANH is maintained P will persist in a state of complete immobility and disordered sensory perception, unable to communicate meaningfully, unable to form and sustain relationships with her family and others and, *if* periodically achieving a low level of awareness, likely on Dr Pinder's evidence to be severely depressed about her level of dependence and inability to interact with environment in context of what is known about her former outlook. P will continue to require a tracheostomy, with the associated suctioning required, and to be tube fed. I am satisfied on the balance of probabilities that this position will not change.
- 74. The challenge to P's dignity presented by this situation is thrown into further and sharp relief by both her expressed views regarding her unwillingness to live in this condition prior to her loss of capacity, and by the evidence before this court of the extent to which P was pre-occupied with, and took pride in her appearance. Against this, the course of action that the applicant and P's family argue is in her best interests will permit a carefully managed, palliated and dignified end consistent with clear views she previously expressed.

CONCLUSION

75. Having given anxious consideration to this very sad case, and with profound regret, for the reasons set out above I am satisfied this court should declare that P lacks capacity to make decisions regarding CANH. Further, in circumstances where I have

concluded that P lacks capacity to decide for herself whether or not to continue to receive CANH, I am satisfied that it is in P's best interests to consent on her behalf to the withdrawal of that treatment, a step that I acknowledge will result in her death.

- 76. I am satisfied that this course of action accords with P's clearly expressed views when she was capacitous. For the reasons I have given, on the evidence before it, the court can be sufficiently certain that P would not in her current situation have consented to ongoing life sustaining treatment, a position that is consistent with all that the court understands about her beliefs, her outlook and her personality, and with the clearly and consistently expressed views of her loving family, borne of their direct experience of her views and wishes and of who she was. In all the circumstances, I am satisfied that the sanctity of P's life should now give way to what I am satisfied was her settled view on the decision before the court prior to the fateful day of her overdose in April 2014.
- 77. The orders and declarations that the court proposes to make are supported by the CCG, the Official Solicitor on behalf of P and the family. In the absence of a concluded care plan, the declarations and orders that I make will be 'in principle' and subject to the receipt by this court of the agreed end of life care plan. Accordingly, I approve the order drafted by counsel at the conclusion of the hearing.
- 78. That is my judgment