Case No: COP 1278226

Neutral Citation Number: [2015] EWCOP 80 IN THE COURT OF PROTECTION

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 30/11/2015

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Before:	
DCIOI C.	

THE HONOURABLE MR JUSTICE MACDONALD

Between:

Kings College Hospital NHS Foundation Trust
- and C
- and V
Respondent
Respondent

Mr Michael Horne (instructed by **Trust Solicitors**) for the **Kings College Hospital NHS Foundation Trust**

Miss Katie Gollop (instructed by Official Solicitor) for the First Respondent Mr John McKendrick (instructed by Bindmans) for the Second Respondent

Hearing date: 13 November 2015

Judgment

Mr Justice MacDonald:

INTRODUCTION

1. A capacitous individual is entitled to decide whether or not to accept medical treatment. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient. In *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 102 Lord Donaldson observed that:

"An adult patient who...suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered... This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."

- 2. This position reflects the value that society places on personal autonomy in matters of medical treatment and the very long established right of the patient to choose to accept or refuse medical treatment from his or her doctor (*voluntas aegroti suprema lex*). Over his or her own body and mind, the individual is sovereign (John Stuart Mill, *On Liberty*, 1859).
- 3. Within this context, where a patient refuses life saving medical treatment the court is only entitled to intervene in circumstances where the court is satisfied that the patient does not have the mental capacity to decide whether or not to accept or refuse such treatment. Where the court is satisfied, on the balance of probabilities, that the patient lacks capacity in this regard, the court may take the decision as to what course of action is in the patient's best interests.
- 4. The question in this difficult and finely balanced case is whether C has the capacity to decide whether or not to consent to the life saving treatment that her doctors wish to give her following her attempted suicide, namely renal dialysis. Without such treatment the almost inevitable outcome will be the death of C. If the treatment is administered the likelihood is that it will save C's life, albeit that there remains an appreciable and increasing possibility that C will be left requiring dialysis for the rest of her life. C now refuses to consent to dialysis and much of the treatment associated with it. She is supported in that decision by her family, and in particular her two elder daughters G and V.
- 5. Within this context, and by reason of a concern on the part of her treating clinicians that C lacks capacity to decide whether or not to consent to dialysis, Kings College Hospital NHS Foundation Trust (hereafter 'the Trust') has applied to this court pursuant to s 15 of the Mental Capacity Act 2005 for a declaration that C lacks capacity to make decisions about her medical care and treatment.
- 6. The Trust further seeks a declaration pursuant to s 4A and s 15 of the Mental Capacity Act 2005 that the Trust and its staff are authorised to provide such medical care and treatment to C as they judge to be clinically indicated, to prevent C from leaving hospital without agreement and to use necessary and reasonable physical and/or chemical restraint for the purposes of giving effect to the declaration with respect to medical care and treatment.

7. On the evening of Friday 13 November 2015, having considered the evidence filed in this matter and having heard oral evidence from three psychiatrists and C's daughter G and the submissions of counsel, I decided that, on balance, C does have capacity to decide whether or not to consent to dialysis. In the circumstances, I dismissed the application of the Trust. I now set out my reasons for coming to that conclusion. This matter was heard in open court. There is a reporting restriction order in force which prohibits the publication of certain information likely to lead to the identification of C as being the subject of an application with respect to serious medical treatment, including the identity of the doctors and other medical professionals treating C.

BACKGROUND

- 8. C is a person to whom the epithet 'conventional' will never be applied. By her own account, the account of her eldest daughters and the account of her father, C has led a life characterised by impulsive and self-centred decision making without guilt or regret. C has had four marriages and a number of affairs and has, it is said, spent the money of her husbands and lovers recklessly before moving on when things got difficult or the money ran out. She has, by their account, been an entirely reluctant and at times completely indifferent mother to her three caring daughters. Her consumption of alcohol has been excessive and, at times, out of control. C is, as all who know her and C herself appears to agree, a person who seeks to live life entirely, and unapologetically on her own terms; that life revolving largely around her looks, men, material possessions and 'living the high life'. In particular, it is clear that during her life C has placed a significant premium on youth and beauty and on living a life that, in C's words, 'sparkles'.
- 9. With respect to youth and beauty, her daughter V states that just as C has never seen herself as a mother, she has never seen herself getting old. Upon being diagnosed with breast cancer in December 2014 when aged forty-nine V relates that C expressed the view that she was "actually kind of glad because the timing was right". It is recorded in C's medical notes that she did not want to discuss the benefits and risks associated with chemotherapy but was "keen not to have any change in size or deficit that will affect her wearing a bikini". She refused to take medication prescribed for the disease because "it made her fat". There appear to have been no concerns expressed regarding C's capacity in this context.
- 10. C's preoccupation with not getting old also manifested itself in other ways. Upon learning that her daughter G was pregnant C's reaction was, says G, one of anger in circumstances where this meant she would be a grandmother and made her feel "past her sell-by date". Within the foregoing context, in her statement V relates that C has often said over the years that she wanted to "go out with a bang" and has been firm in her conviction that, with regard to growing old, she "just would not let it happen".
- 11. C's emphasis on money, material possessions and 'living the high life' is also well established by the evidence in this case. From the history of her four marriages provided by V it would appear that C has, over the course of those four marriages, considered a downturn in the financial fortunes of her husbands an entirely reasonable ground for moving on and has taken requests that her spending be curtailed or limited to be unreasonable. The value that C places on wealth and possessions is further

- demonstrated by her statement to V that, her fortunes having suffered a downturn in recent times, she does not want to "live in a council flat" or to "be poor".
- 12. Despite her patent faults C is dear to her daughters. V relates that she and G have learnt to accept their mother for who she is: complexities, seeming contradictions, blind spots, self-centred and manipulative behaviour, excruciating honesty and all. V tells me that she has accepted that there is no point in trying to make C a 'typical mother' in the same way she could not have been a 'traditional wife' to her four husbands. She is who she is says V and summarises the position as follows:

"My mother's values, and the choices that she made have always been based on looks (hers and other people's), money, and living (at all costs) what she called her "sparkly" lifestyle...her life was, from her point of view, a life well lived. I have never known her express regret, or really to take responsibility for anything, including the choices she has made".

- 13. Over the past year the progress of C's life has, sadly, followed a trajectory that has moved away from what she terms her "sparkly" lifestyle. As I have already noted, C was diagnosed with breast cancer in December 2014. She underwent a lumpectomy in January 2015 and radiotherapy in March 2015, with treatment concluding in May 2015. C has said that, understandably, this placed her under some stress. In August 2015 C experienced the acrimonious breakdown of a long term relationship. This also resulted in the loss of her business and the financial security attendant thereon, the loss of her home and the generation of significant debt. C was also the subject of arrest and criminal charges arising from an incident that occurred during the breakdown of her relationship. This situation is described in the report of Dr R as exposing C to 'back to back psycho-social stressors'.
- 14. On 7 September 2015 C attended V's house and asked where her Veuve Clicquot was. Later that day C attempted to commit suicide. The attempt was premeditated and planned. C went to a beach and took sixty paracetamol tablets with champagne. The attempt was not successful (C later told her daughters that she "royally cocked it up"). When C awoke she became worried about the pain that she might suffer and called her general practitioner who advised her to call an ambulance. She was admitted to a local hospital for urgent care and subsequently transferred to King's College Hospital on 29 September 2015. Whilst at the local hospital V relates that C stated that she would try to kill herself again and that she was adamant that she wanted to die.
- 15. The consequences of C's attempted suicide have been grave and are described in detail in C's medical records and in the statements of Dr L, liver consultant and Dr S, consultant nephrologist. In summary, as a result of her paracetamol overdose C suffered an injury to her liver and an acute injury to her kidneys. Since admission to hospital C has, consequently, required renal replacement therapy. That therapy was provided initially by a 'filtration' machine and thereafter by intermittent haemodialysis for four hours three times per week.
- 16. Following a period of intensive treatment after the overdose, C made slow but progressive improvement in her liver function. However, an improvement in her kidney function has yet to occur with her kidneys showing no signs of significant

recovery. Dr L is clear that the ongoing care of C is now predominantly supportive in nature save for the essential requirement of kidney dialysis. The anticipated duration of that treatment is from a minimum of six weeks up to a maximum of several months. As at 6 November Dr L was of the view that the outlook for C's kidney function was unclear but that, generally, her doctors anticipated a recovery in due course. Dr L described the view regarding C's kidney function on that date as 'cautiously optimistic'.

- 17. In a statement dated 9 November 2015 Dr S observes that the 'overwhelming majority' of people who suffer an acute kidney injury as a result of a paracetamol overdose recover independent kidney function, usually within four to six weeks. However, he further notes that in circumstances where C is now nearly nine weeks from her overdose, arriving at a confident prognosis is made more difficult. In C's medical records Dr S is recorded as informing C on 5 November 2015 that her prognosis remained unpredictable and that, even were the damage to her kidneys to be potentially reversible, the prognosis would remain uncertain.
- 18. In his statement Dr S explains that the most likely explanation for the current state of C's kidney function is a combination of paracetamol related kidney injury, severe liver injury and several episodes of infection requiring antibiotic treatment, and that the most likely outcome remains that C will recover independent kidney function over the course of several months. Dr S however makes clear that it is possible that C has sustained irreversible damage to her kidneys in the form of cortical necrosis. The way to establish definitively whether this is the case for C would be to perform a kidney biopsy. At present however this is a high risk procedure due to C having abnormal blood clotting levels as a result of her liver injury. A kidney biopsy will become less risky as C's liver recovers.
- 19. Dr S states that C may well be left with an element of chronic kidney damage. Within this context, if C recovers kidney function to the point where she does not need renal replacement therapy then Dr S would expect C's kidney function to have minimal effect on C's ability to continue as she had prior to the overdose. However, if C does not recover kidney function Dr S is clear that she would require regular renal replacement therapy in order to stay alive. The options for such replacement therapy would be a continuation of the haemodialysis that C currently has, peritoneal dialysis or a kidney transplant.
- 20. In an updating statement dated 11 November 2015 Dr L opines that C's prognosis "remains excellent with survival fully anticipated". Dr L records that restoration of C's liver function to normal is anticipated within a four to six week period. Dr L further records that C's kidney function has still yet to recover but anticipates an 85 to 95% chance of this occurring having regard to the progression seen in a large majority of similar cases. However, like Dr S, Dr L acknowledges that, with the passage of time, the likelihood of full recovery diminishes. Dr L estimates that if C is not fully recovered within a period of three months, later recovery is unlikely, with the chances of delayed restoration after three months estimated at less than 20%. In such circumstances C would require long term renal replacement therapy.
- 21. Dr S makes clear that if C does not have further dialysis and continues to have minimal kidney function, she will become progressively unwell as levels of potassium and acid in her blood increase to dangerous levels. These levels will typically become

life threatening between three and seven days following the last haemodialysis session. If C drinks during this period then she will also endure fluid build up on her lungs and insufficient oxygen in her bloodstream as a result. The risks of a sudden cardiac event or deterioration will increase after more than three days without dialysis. If C's kidney function remains poor and she passes very little urine, it is likely that C will die within five to ten days of having no dialysis. C would become progressively drowsy and possibly confused after several days although a sudden cardiac arrest and death is possible at any point.

- 22. Were doctors to have to force C to receive dialysis against her consent Dr S makes clear that this would be a significant undertaking. He states that were doctors to attempt to administer dialysis to C in circumstances where C took measures to try and stop such treatment the treatment would immediately become unsafe for C (and potentially for medical staff). In such circumstances, Dr S makes plain that in order to dialyse C against her will she would need to be sedated with that sedation being heavy enough to render her, essentially, unconscious for the duration of the dialysis. In order to achieve this safely the procedure would need to be undertaken in a high dependency setting. There are, of course, risks associated with heavy sedation, including respiratory depression and low blood pressure which may in turn necessitate further intervention including intubation and ventilation. Finally, Dr S states that a person seeking to avoid dialysis may remove the dialysis tubes when able to do so, resulting in the need to insert a dialysis tube into a large vein each time and under sedation. There is a risk of bleeding and infection each time this is done, which risk is significantly increased in C given her abnormal clotting. There is also a risk of damage to veins, thereby increasingly restricting venous access. Dr S opines that the minimum frequency of dialysis in this context would be once every five days, although the risks of a sudden cardiac event or deterioration increase over time after more than three days without dialysis.
- 23. It is within the context of this background C now refuses to undertake further haemodialysis. The parties are agreed that I should deal with the issue of capacity only at this stage. Accordingly, as set out above, the issue for the court is whether, at this time, C has the mental capacity to decide whether or not to consent to the life saving treatment that her doctors wish to continue to give her.

THE LAW

24. The law that I must apply to the facts in this case in reaching my decision as to capacity is set out in the Mental Capacity Act 2005. 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.
- 25. The following cardinal principles flow from the statute (*PH v A Local Authority* [2011] EWHC 1704 (COP) at [16]). First, 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]).
- 26. Second, 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.
- 27. Third, 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)).
- 28. Fourth, a person is not to be treated as unable to make a decision merely because he or she makes a decision that is unwise. It is important in this regard to recall the words of Peter Jackson J in *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 (COP) at [7]:

"The temptation to base a judgment of a persons capacity upon whether they seem to have made a good or bad decision, and in particular on whether they have accepted or rejected medical advice, is absolutely to be avoided. That would be to put the cart before the horse or, expressed another way, to allow the tail of welfare to wag the dog of capacity. Any tendency in this direction risks infringing the rights of that group of persons who, though vulnerable, are capable of making their own decisions. Many who suffer from mental illness are well able to make decisions about their medical treatment, and it is important not to make unjustified assumptions to the contrary."

- 29. Likewise, 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]).
- 30. Within these contexts, the fact that a decision not to have life saving medical treatment may be considered an unwise decision and may have a fatal outcome is not of itself evidence of a lack of capacity to take that decision, notwithstanding that other members of society may consider such a decision unreasonable, illogical or even immoral, that society in general places cardinal importance on the sanctity of life and that the decision taken will result in the certain death of the person taking it. To introduce into the assessment of capacity an assessment of the probity or efficacy of a

decision to refuse life saving treatment would be to introduce elements which risk discriminating against the person making that decision by penalising individuality and demanding conformity at the expense of personal autonomy in the context of a diverse, plural society which tolerates a range of views on the decision in question (see *Mental Incapacity* (1995) (Law Comm No 231) (HC 189), para 3.4).

- 31. Fifth, 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]).
- 32. Sixth, 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 1920 (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)).
- 33. The order in which the relevant terms of the Mental Capacity Act 2005 are drafted places the 'diagnostic test' in s 2(1) before the 'functional test' in s 3(1). However, having regard to the wording of s 2(1), namely, "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" (emphasis added), the order in which the tests are in fact applied must be carefully considered. In *York City Council v C* [2014] 2 WLR 1 at [58] and [59] McFarlane LJ (with whom Richards and Lewison LLJ agreed) held as follows:

"It would be going too far to hold that in approaching matters in this way Hedley J plainly erred in applying the law. His judgment refers to the key provisions and twice refers to the nexus between the elements of an inability to make decisions set out in s 3(1) and mental impairment or disturbance required by s 2(1). There is, however, a danger in structuring the decision by looking to s 2(1) primarily as requiring a finding of mental impairment and nothing more and in considering s 2(1) first before then going on to look at s 3(1) as requiring a finding of inability to make a decision. The danger is that the strength of the causative nexus between mental impairment and inability to decide is watered down. That sequence - 'mental impairment' and then 'inability to make a decision' - is the reverse of that in s 2(1) - 'unable to make a decision ... because of an impairment of, or a disturbance in the functioning

of, the mind or brain' [emphasis added]. The danger in using s 2(1) simply to collect the mental health element is that the key words 'because of' in s 2(1) may lose their prominence and be replaced by words such as those deployed by Hedley J: 'referable to' or 'significantly relates to'...Approaching the issue in the case in the sequence set out in s 2(1), the first question is whether PC is 'unable to make a decision for herself in relation to the matter', the matter being re-establishing cohabitation with NC now that he is her husband and now that he is has regained his liberty."

- 34. Within this context, it is important to remember that 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 'impairment of, or a disturbance in the functioning of, the mind or brain' required by s 2(1) of the Act.
- 35. In this case the Trust bases its submissions regarding the 'functional test' squarely on section 3(1)(c) of the 2005 Act, which provides that a person is unable to make a decision for himself if he is 'unable to...use or weigh' the relevant information as part of the process of making the decision (as the disjunctive 'or' comes after the negative, 'unable to' in s 3(1)(c) the subsection requires the person asserting a lack of capacity to demonstrate an inability on the part of the individual to use *and* weigh the relevant information).
- 36. In *PCT v P*, *AH and The Local Authority* [2009] COPLR Con Vol 956 at [35] Hedley J described the ability to use and weigh information as "the capacity actually to engage in the decision making process itself and to be able to see the various parts of the argument and to relate one to another".
- 37. Within the context of s 3(1)(c) it is not necessary for a person to use and weigh every detail of the respective options available to them in order to demonstrate capacity, merely the salient factors (see *CC v KK and STCC* [2012] EWHC 2136 (COP) at [69]). Even though a person may be unable to use and weigh some information relevant to the decision in question, they may nonetheless be able to use and weigh other elements sufficiently to be able to make a capacitous decision (see *Re SB* [2013] EWHC 1417 (COP)).
- 38. It is important to note that s 3(1)(c) is engaged where a person is *unable* to use and weigh the relevant information as part of the process of making the decision. What is required is that the person is able to employ the relevant information in the decision making process and determine what weight to give it relative to other information required to make the decision. Where a court is satisfied that a person is able to use and weigh the relevant information, the weight to be attached to that information in the decision making process is a matter for the decision maker. Thus, where a person is able to use and weigh the relevant information but chooses to give that information no weight when reaching the decision in question, the element of the functional test comprised by s 3(1)(c) will not be satisfied. Within this context, a person cannot be considered to be unable to use and weigh information simply on the basis that he or she has applied his or her own values or outlook to that information in making the decision in question and chosen to attach no weight to that information in the decision making process.

39. Finally, whilst the evidence of psychiatrists is likely to be determinative of the issue of whether there is an impairment of the mind for the purposes of s 2(1), the decision as to capacity is a judgment for the court to make (see *Re SB* [2013] EWHC 1417 (COP)). In *PH v A Local Authority* [2011] EWHC 1704 (COP) Baker J observed as follows at [16]:

"In assessing the question of capacity, the court must consider all the relevant evidence. Clearly, the opinion of an independently-instructed expert will be likely to be of very considerable importance, but in many cases the evidence of other clinicians and professionals who have experience of treating and working with P will be just as important and in some cases more important. In assessing that evidence, the court must be aware of the difficulties which may arise as a result of the close professional relationship between the clinicians treating, and the key professionals working with, P. In Oldham MBC v GW and PW [2007] EWHC136 (Fam) [2007] 2 FLR 597, a case brought under Part IV of the Children Act 1989, Ryder J referred to a "child protection imperative", meaning "the need to protect a vulnerable child" that for perfectly understandable reasons may lead to a lack of objectivity on the part of a treating clinician or other professional involved in caring for the child. Equally, in cases of vulnerable adults, there is a risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective."

THE EVIDENCE

40. In determining the issue of capacity in this case I have had the benefit of reading statements from Dr L, Dr S, the Official Solicitor and from V and G. I have also had the benefit of psychiatric reports from Dr R (Consultant Liaison Psychiatrist at Kings College Hospital), Professor P (Professor of General Psychiatry at Kings College) and Dr Stevens (retired Consultant Psychiatrist). I have heard oral evidence from Dr R, Professor P, Dr Stevens and G. In addition to this evidence I have also read the medical records for C, including the clinical notes which provide a running record of C's treatment and, importantly, her interactions with medical staff.

DrR

- 41. C has been assessed by Dr R with respect to her capacity on a number of occasions. In a report dated 6 November 2015 Dr R concludes that C does not have capacity to decide whether or not to receive dialysis. Dr R considers that this is by reason of C being unable to use and weigh the information required as part of the process of making a decision about whether to undergo dialysis, that inability being consequent upon an impairment of, or a disturbance in the functioning of, C's mind or brain which Dr R considers, tentatively, may comprise a personality disorder.
- 42. After accepting that the use and weigh criterion is the most difficult of the four criteria by reason of the degree of subjective judgment involved, in respect to Dr R's assessment that C is unable to use and weigh the information required as part of the process of making a decision he confirmed in his oral evidence that the two key areas of concern were what he assessed to be (a) C's lack of belief in, and inability to use

- and weigh her positive prognosis notwithstanding her doctors reassuring her that the prognosis is positive and (b) C's inability to contemplate a future that includes her recovery, having closed her mind to this.
- 43. Overall, Dr R states he has major concerns regarding her ability to use and weigh and is concerned that C has not articulated a position that demonstrates she has used and weighed all evidence in relation to the outcome. Dr R relied on the following examples in this regard in his report and in his oral evidence:
 - i) On 25 September 2015 C was noted to have "an overvalued idea that her quality of life will not improve and that she can die in a hospice."
 - ii) On 29 September 2015 C refused dialysis. Dr R was concerned that C's capacity to "weigh in the balance the risks and benefits of accepting/refusing treatment" was compromised by "very rigid thinking style and her distorted cognition such as black and white thinking and catastrophic thinking e.g. that she will forever require dialysis and will never recover to a stage where she can live an independent life again". Within this context Dr R concluded that C was unable to use or weigh information relevant to the decision being made. It is important to note that later on 29 September 2015 C changed her mind and consented to dialysis (which I deal with in more detail below);
 - iii) On 20 October 2015 C is recorded as stating that she does not want a life dependent on dialysis and of poor quality and seemed to dismiss the medical opinion that she has every chance of making a good recovery and leading a fulfilling and normal life and that she was expressing rigid ideas about not wanting treatment on that day.
 - on 3 November 2015 C again refused dialysis. Dr R was concerned that the main driver of C's decision appeared to be her categoric belief that the timescale given to her for recovery had passed. C considered that this meant she would not recover and did not want a lifetime of dialysis. Within this context, Dr R concluded that "She is unflinching in her belief about this. I think this could be significantly influenced by her personality traits and as such are affecting her ability to use and weigh evidence presented to her thereby affecting adversely her ability to make a capacitous decision."
 - v) On 5 November 2015 Dr R recorded that, having against spoken to C, the concerns he had on 3 November subsisted. In his report dated 6 November 2015 Dr R records his conversation with C on 5 November as follows "C states she remains adamant that she does not wish to continue with dialysis treatment. The reasons, as she tells me, are that she has never wanted to have it (despite many weeks of engaging), she has acquiesced rather than engaged enthusiastically. Now she finds it painful, exhausting and she has had enough. She states she knows she will die as a result of not having it. She believes herself to have the capacity to make this decision...she also appears to have taken a very concrete categorical cognitive position around the inevitability of death despite her treating doctors' view of her prognosis. She believes she has no hope of recovery as she is now through the period of expected recovery as described to her. She is unflinching in her belief about this." Within this context, Dr R concluded "This unexplained and seemingly irrational decision

- is not met with significant using and weighing demonstrably ending with a capacitous but objectively assessed unwise decision."
- vi) On 6 November Dr L noted that C was frustrated at the delay in recovery and was exhibiting an apparent indifference to the consistent message provided by her medical team that recovery would occur.
- vii) On 9 November 2015 Dr R saw C again and noted that "We also spoke in more detail about being able to envisage a future in which she was back up on her feet again with no line in her neck and no pain. She stated that this was not possible 'they have told me before that I would do that and I am still here' 'I can't go on like this for months or months or forever'."
- viii) On 10 November 2015 Dr R again spoke to C and recorded that, when he pressed C about the reasons for making her decision to refuse treatment, "it comes back to her expressed belief that there is no hope 'a tiny sliver of hope' as she put it today, that she will get better. When I challenge her about this gently and ask what she hears when the doctors state they remain optimistic that she will recover from this acute phase, she tells me she hears that she cannot do what she wants to do."
- 44. As to the existence of an impairment of, or a disturbance in the functioning of, C's mind or brain Dr R was reluctant to diagnose a personality disorder in circumstances where C remains gravely ill. However, whilst Dr R considered it risky to make a diagnosis during the acute phase of a medical condition, he is satisfied that C's symptoms are 'in fitting' with a personality disorder. Within this context, Dr R acknowledged that the question of whether a particular person has a histrionic or narcissistic personality disorder, as opposed to simply a very strong or difficult personality can be an area of some controversy and said that there are no validated tools in this area to ascertain a baseline of 'normal' in the context of diagnosing personality problems.
- 45. As to the question of causation, Dr R gave evidence that C's presenting behaviour could be the result of a personality disorder or could be the result of her belief system. Dr R further accepted that the factors he considered militated against C being able to use and weigh relevant information (namely, the black and white thinking and rigidity in relation to her prognosis) were not listed on diagnostic criteria for histrionic or narcissistic personality disorder, although they are a common symptom of the same. Overall, Dr R opined that the rigid, 'black and white, cognitive position that, in Dr R's view, is preventing C from reaching what he describes as "a balanced, nuanced, used and weighed position", can be explained by the thinking associated with the dysfunction of disorders of personality in C.
- 46. Dr R made clear in his oral evidence that he considered this case to be, as he put it, an "incredibly challenging" one. He was further clear that if the court determined that C has capacity he would accept that decision.

Professor P

47. A second opinion as to capacity was obtained by the Trust from Professor P. In oral evidence he too described this as "a clearly difficult case". His opinion is based on an

- hour long interview with C and an hour long interview with V and G. Professor P also discussed C's case with Dr R and read his draft report.
- 48. As a result of his assessment Professor P came to the conclusion that C lacked capacity to decide whether to undergo dialysis. Like Dr R, Professor P considered that C was unable to use and weigh the information required as part of the process of making a decision, that inability being due to a combination of an underlying diagnosis of histrionic personality disorder and her current circumstances.
- 49. Specifically, the Professor concluded that C is unable to use and weigh the information required as part of the process of decision making because, he believes, C demonstrated no ability to consider and weigh alternative futures, no ability to place herself in her daughters' shoes when considering the effect of her refusing treatment or to weigh the impact on them of her suicide and no ability in respect of her prognosis to accept anything other than the inaccurate view that the damage to her kidneys is irreversible and she could not survive without permanent dialysis. Professor P believes that C is exhibiting what he describes as a "petulant" response to a lack of timely recovery. In oral evidence the Professor reiterated that the evidence of C's inability to use and weigh comprises her inability to project herself into the future and her insistence that the future is not what the medial assessment says it will be.
- 50. With respect to the existence of an impairment of, or a disturbance in the functioning of, C's mind or brain Professor P diagnosed C as having a histrionic personality disorder (ICD-10 F60.4). The Professor based his diagnosis on both his interview with C and the longitudinal information concerning C's life history provided by her family.
- 51. With respect to causation, like Dr R, Professor P was cautious on whether it is C's diagnosed personality disorder that drives her alleged inability to use and weigh information or simply her character traits such as stubbornness or 'bloody mindedness'. On balance however, Professor P favoured the conclusion that C's alleged inability to use and weigh information relevant to the decision in question, and specifically information concerning her future prognosis, is a product of a personality disorder.

Dr Stevens

- 52. Dr Stevens was jointly instructed by the Trust and the family as an independent expert witness by a letter of instruction dated 10 November 2015. In examining the evidence provided by Dr Stevens I note and take into account that he was, by virtue of the particular circumstances of this case, working to a very tight timescale indeed with respect to the provision of his expert opinion. However, as I was forced to note during the course of the hearing, there are, unfortunately, significant shortcomings with respect to Dr Stevens' report.
- 53. Dr Stevens' report concludes that C does have capacity to decide whether or not to receive dialysis. Dr Stevens' report however contains no account of the process by which he reaches that conclusion or his reasons for doing so. Nor does Dr Stevens' report contain a clear and detailed account of the questions he asked C in order to assess her capacity in this respect nor the answers she gave. A short adjournment to secure Dr Stevens' contemporaneous notes of his assessment did not result in any

greater illumination. Further, during the course of examination in chief it became apparent that the one direct quote from C that Dr Stevens does set out in his report (and one which suggests C clearly accepts that she has a positive prognosis and has weighed it in her decision) occurred after C had been medicated with oxycodone (a synthetic opiate). This was not mentioned in Dr Stevens' report. Overall, Dr Stevens' report failed to evidence rigorous adherence to good practice when assessing capacity as set out in the Mental Capacity Act 2005 Code of Practice, and in particular Paragraph 4.49. These difficulties notwithstanding however, it is important for the court to note the following factual information contained in the report of Dr Stevens when coming to its own determination in respect of C's capacity.

54. Although at a point where she had been administered a synthetic opiate pain killer some two hours previously, C told Dr Stevens on 10 November 2015 that "I know that I could get better; I know that I could live without a health problem, but I don't want it; I've lost my home; I've lost everything I'd worked for; I've had a good innings; it's what I have achieved." Further, Dr Stevens records in his report (although it is not reflected in his contemporaneous notes) that C:

"made very clear to me that she understands and has retained the information that her liver is making a good recovery and that her kidneys are recovering, albeit more slowly, such that her doctors wish her to undergo thrice weekly haemodialysis for some months to come. C also understands and has retained the information that her doctors expect her kidney function to recover such that haemodialysis can be discontinued at some point in 2016 and that her medical quality of life can be expected to improve thereafter. In response to my further exploration, C told me that she had thought a great deal about her medical condition and that, despite appreciating that she has been given a good prognosis, she remains steadfastly determined to die as soon as possible."

55. Having assessed C, Dr Stevens diagnosed a narcissistic personality disorder which constituted an impairment or disturbance in the functioning of her mind. Having regard to his exchanges with C Dr Stevens considered that C was able to make a decision at that time regarding the withdrawal of active medical treatment.

Medical Records

- 56. Within the context of the foregoing psychiatric evidence, it is important to consider the content of C's medical records which are before the Court. Those records are important for two reasons. First, they give a clear picture of the information that C was being given concerning her prognosis in the period leading up to her refusal of further medical treatment. Second, the medical records give a picture of how C treated that information when it was provided to her. I draw on aspects of the medical records below when setting out my reasons for the conclusions I have come to in this case.
- 57. At this point however I pause to note that it is clear from the medical notes that different doctors have taken different views in relation to C's capacity to refuse medical treatment. On 25 September 2015, when C stated that she could refuse dialysis, would refuse dialysis and would move to a hospice, the notes make clear that C's capacity to refuse treatment was queried but that she was deemed competent to

refuse treatment at that time. The day before C refused treatment for the first time on 29 September 2015 it was considered that C appeared to have capacity (although she was noted to be intermittently encephalopathic). On 18 October 2015 Dr K (SHO) considered that C displayed capacity when expressing her wish to forgo further treatment and to move to a hospice. On 19 October 2015 Dr V recorded that C displayed signs indicative of capacity (understanding, weighing up, retaining and repeating information) although capacity was not clear cut. On 2 November 2015 Dr N took the view that C appeared to have capacity but noted that a psychiatric review was required. As noted above, thereafter both Dr R and Professor P took the view that C lacked capacity to decide whether or not to undergo dialysis.

Official Solicitor

- 58. I have not had the opportunity to meet C. She is too ill to attend court and given the need for an urgent decision to be made in this case there has not been time to arrange for me to attend hospital to meet with her. I do however have the benefit of two comprehensive attendance notes prepared by the representative of the Official Solicitor who saw C in hospital on 10 November 2015 and on the morning of this hearing on 13 November 2015.
- 59. It is of note that when she was seen on 10 November 2015 C stated "I don't want to do weeks or months of this...I have been through horrible stuff. I am not prepared to do that again. They are doing their best to do everything they can for me and unfortunately that is not what I want". Also of note is that C acknowledged the possibility that her kidneys will recover, saying "I am not prepared to wait for the possibility that my kidneys will get better". C did not reject the possibility of recovery out of hand but chose to highlight the uncertainties when asked whether she believed the doctors when they said she would get better, "Everything is 'ifs and ands and pots and pans'. My quality of life won't be what I want. I will be a burden". Later, when again pressed regarding the fact that the doctors were saying she might return, physically, to where she was in the past and, although they could not say when, they felt she would get better C responded "No, I'm not going to have weeks of this. I am at peace with myself".
- 60. Towards the end of her appointment with the representative of the Official Solicitor, C was asked whether she would make the same decision, i.e. to refuse treatment, if she knew she was going to get better, she responded "Yes, I don't want to do this life and the way they are presenting it. I am hurting everywhere." Later she said "I know they need to save lives. But I've chosen a different route." When asked whether, with professional support she would come to a different conclusion, "No, it comes from within. I don't want to fight for it. I don't want to be a burden. I've been through so much. I don't think mentally I'll be the same". At the end of the meeting C stated that "I want someone to say I can't do this anymore. Everyone makes a choice. It would be nice if they could give me some choice. I am not getting any choice. I am getting wheeled along. It's a bit unfair." When C saw the representative of the Official Solicitor again on the morning of the hearing on 13 November 2015 she maintained that she had capacity to make the decision to refuse further treatment.

- 61. In this case, C's daughter V has provided a statement of evidence to the court. C's daughter G has also provided a short statement indicating her agreement with that which V has said. At this hearing, V felt unable to speak to her statement due to the emotions generated by the current situation. In the circumstances, G gave oral evidence before the court. She did so with candour and great dignity.
- 62. G made clear that C's family believe that she does have capacity to decide whether or not to refuse treatment. In particular, G was clear that her mother has considered and weighed her prognosis as provided by the doctors when reaching her decision. G's statement makes clear that she agrees with V's account of the multidisciplinary meeting on 3 November 2015. V states that following Professor G telling C that her prognosis was good and that she could "be out with a drink in your hand by Christmas" and, within that context, C agreeing to "give it a go", C changed her mind a short time later. V makes clear her view that "She had clearly used the time to consider the prospect of having what Professor P described as a 'tolerable life', and decided that, although with the more optimistic prognosis, it required some thought, she still did not want to live." V further makes clear in her statement that C "repeatedly told us that she didn't care whether her kidneys improved or not, and that she had thought about it, and that she wanted to die regardless. She – in the full knowledge that it was entirely possible that she might make a full recovery – said that if her kidney function improved, and she were discharged, that she would 'throw [herself] under a train". V confirms that it was at this point that she concluded that C had thought through her decision and understood the choice she had made.
- 63. Within this context, G was also clear that in her conversations with her mother C has considered the alternatives, including continued treatment and has rejected them. In her statement, V summarises her position and that of G as follows:

"As I have said above, my mother would never have wanted to live at all costs. Her reasons for trying to kill herself in September and for refusing dialysis now are strongly in keeping with both her personality and her long held values. Although they are not reasons that are easy to understand, I believe that they are not only fully thought through, but also entirely in keeping with both her (unusual) value system and her (unusual) personality. Her unwillingness to consider 'a life she would find tolerable' is not a sign that she lacks capacity; it is a sign that what she would consider tolerable is different from what others might. She does not want any life that is on offer to her at this stage. Put bluntly, her life has always revolved around her looks, men, and material possessions: she understands that (as put to her by Professor [P]) other people have failed relationships, feel sad and continue living, but for her, as she has said, she doesn't want to 'live in a council flat', 'be poor' or 'be ugly' (which she equates with being old). As is set out in the notes, she truly means it when she says 'I have lost everything this year', and that being the case, she doesn't want to accept any of the options on offer to her as – as she sees it – an 'old grandma', even were her kidneys to fully recover. 'Recovery' to her does not just relate to her kidney function, but to regaining her 'sparkle' (her expensive, material and looks-orientated social life) which she believes she is too old to regain. Again, the references in the notes to her talking about being 'sociable, hosting parties and going out with the girls' are fitting: to those who know her well, her entire identity has been built around being a self-described 'vivacious and sociable person who lives life to the full and enjoys having fun'".

SUBMISSIONS

- 64. On behalf of the Trust Mr Horne concedes, very properly, that this is a finely balanced case that sits close to the border that runs between an individual with capacity making an unwise decision and an individual lacking capacity to make the decision in question.
- 65. On balance the Trust submits C lacks the capacity to decide whether or not to receive dialysis on the basis that she is unable to use and weigh information relevant to the decision as part of the process of making that decision. Specifically, the Trust submits that the examples given by Dr R show that (a) C lacks belief in, and is unable to use and weigh her positive prognosis and (b) that C is unable to contemplate a future that includes her recovery, having closed her mind to this. The Trust submits that this constitutes an inability to use and weigh information for the purposes of s 3(1)(c) and that this inability is because of the impairment of, or a disturbance in the functioning of, the mind or brain for the purposes of s 2(1) comprised of the personality disorder diagnosed by Professor P and Dr Stevens. In the words of Dr R, the Trust submits that C's decision to refuse treatment is not reached with significant using and weighing of information demonstratively ending with a balanced, nuanced, used and weighed position constituting a capacitous but objectively assessed unwise decision. Again, the Trust submits that this situation is arrived at because of the personality disorder under which C labours.
- 66. By contrast, having heard the oral evidence received by the court at this hearing the Official Solicitor submits that C does have capacity to decide whether or not to refuse treatment.
- The Official Solicitor submits that the evidence in this case points not to C being 67. unable to use and weigh information concerning her prognosis and future but, rather, to C taking into account that information and choosing to give it no weight as against other relevant information more important to her in the context of her outlook and values when coming to her decision. Within this context, citing Re SB (A Patient: Capacity to Consent to Termination) [2013] EWHC 1417 (COP) the Official Solicitor submits that, even were the court to consider C's approach to her prognosis as overly rigid or 'black and white' C has given many other valid reasons for refusing treatment more important to her than her prognosis, which reasons evidence capacitous decision making within the context of her particular outlook and belief system. In any event, the Official Solicitor cautions the court against characterising C's attitude towards her prognosis as rigid, or 'black and white' or irrational in circumstances where that prognosis remains uncertain and is worsening the longer C goes without her kidneys showing any sign of recovery. Were the court to conclude that C is unable to 'use or weigh' information relevant to the decision, the Official Solicitor further submits that the Trust cannot establish a causal link between this inability and C's personality disorder in circumstances where the inability in question could equally be attributed to C's belief system or stubborn character.

- 68. The submissions made on behalf of V are akin to those made on behalf of C by the Official Solicitor. V contends that her mother has the capacity to decide whether to accept treatment.
- V submits that the Trust places the test for capacity too high by demanding from C a 69. closely reasoned "balanced, nuanced, used and weighed position" in respect of her medical prognosis. V submits that on a proper application of the criteria set out in the 2005 Act the evidence before the court shows C has made a clear and capacitous decision, which decision she has maintained, after using and weighing the information relevant to that decision in accordance with her particular outlook and values. Thus, V submits, C has reached a clear and reasoned decision by giving weight to the factors that are important to her (a risk of a life lived on dialysis that is unacceptable to her, a risk of long term disability that is unacceptable to her, exhaustion with treatment and her wish not to endure further weeks or months of the same, her wish not to continue to endure the symptoms and pain associated with treatment, the risk she will not be able to attain her former "sparkly" lifestyle, her desire not to get old and lose her appearance and her wish to attain her original goal of ending her life) and no weight to the factors that are not (namely, the possibility that she might recover to a point where she can live without dialysis, the possibility of a future life that is 'tolerable' and the impact of her death on those who care for her) within the context of her (very unusual) set of values and outlook. V submits that this is the very essence of a capacitous decision. Again, were the court to conclude that C is unable to use and weigh information relevant to her decision, V submits that the Trust cannot establish a causal link between this inability and C's personality disorder in circumstances where the inability in question could equally be attributed to C's belief system and stubborn character.

DISCUSSION

- 70. In this difficult case I have come to the conclusion that, on balance, C does have capacity to decide whether or not to receive dialysis. My reasons for so deciding are as follows.
- 71. The first question for the court is whether the Trust has established on the balance of probabilities C is unable to make a decision about the matter in hand having regard to the matters set out in s 3(1) (the so called 'functional test'). The Trust accepts that C is able to understand the information relevant to the decision, to retain that information and to communicate her decision. In relation to the remaining element of the functional test I am not satisfied that the Trust has proved to the requisite standard that C is *unable* to use and weigh the information relevant to the decision in question.
- 72. Notwithstanding the submission of the Trust, I am not satisfied that C lacks belief in her prognosis or a future that includes her recovery to the extent she cannot use that information to make a decision, or that C is unable to weigh her positive prognosis and the possibility of a future recovery in the decision making process. In my judgment, the evidence in this case, when viewed as a whole, is indicative of C acknowledging that her prognosis is positive, that there is a possible future in which she survives and of her weighing that information in her decision making process.
- 73. The entries in the medical records which I have referred to above show that C has, on a number of occasions over the span of her treatment, tacitly acknowledged that her

prognosis is positive if she maintains treatment and has weighed that against other factors.

- 74. For example, on 29 September 2015 the rationale expressed by C for refusing treatment was that she believed she may need dialysis for the rest of her life, saw a bleak future if she could not have a life of socialising, drinking and partying with friends, that getting old scared her both in terms of illness and appearance. C was recorded by Dr O (Liver SHO) as being clear in her understanding that without dialysis, adequate nutrition and treatment of her liver she would die and, within that context, as being able to take in the medical advice and fully understood the risk of refusing treatment. Following interventions from her father and a friend on 29 September, C changed her mind and consented to treatment. It is clear from the medical records that C appears, with the assistance of her father and her friend, to have undertaken an exercise of using or weighing information as it is recorded that an hour was spent talking to C about her grave medical condition, her chances of recovery, and her prognosis for the future.
- 75. On 1 November 2015 C stated that she did understand that she would die if she stopped dialysis and this would not necessarily be pleasant. She is recorded as listening to the positive prognosis and quality of life on long term dialysis following which C said she understood it but that her 'heart is not in it'.
- 76. On 2 November C stated that she felt fed up and exhausted, was hoping her kidney function would improve in 6 weeks but it hadn't, could not imagine herself dependent on dialysis, felt it would be pointless to continue if she could not recover to a functional level where she could continue with her previous lifestyle, felt she did not have the mental health to continue with the treatment and therefore she was determined not to continue with the treatment. C is recorded as having understood that this would shorten her life expectancy.
- 77. On 5 November 2015 Dr R recorded C reasoning her position as follows, "C states she remains adamant that she does not wish to continue with dialysis treatment. The reasons, as she tells me, are that she has never wanted to have it (despite many weeks of engaging), she has acquiesced rather than engaged enthusiastically. Now she finds it painful, exhausting and she has had enough. She states she knows she will die as a result of not having it".
- 78. On 9 November 2015 C told Dr R that she knew what the doctors were doing and were not angry with them, as they were just trying to save her life but she did not wish to be saved. When speaking to the representative of the Official Solicitor on 10 November 2015 C acknowledged the possibility that her kidneys will recover, saying "I am not prepared to wait for the possibility that my kidneys will get better". On 9 November 2015 C told Dr R that she knew what the doctors were doing and were not angry with them, as they were just trying to save her life but she did not wish to be saved. When Dr R spoke to C about being able to envisage a future when she was back on her feet again with no line in her neck and no pain C is recorded as saying "they have told me before that I would do that and I am still here"... "I can't go on like this for months and months or forever."
- 79. There is also evidence before the court of C expressly acknowledging her positive prognosis and weighing the same. On 3 November 2015 V recalled that in deciding

not to continue with treatment following the MDT meeting on that day C "had clearly used the time to consider the prospect of having what Professor P described as a 'tolerable life', and decided that, although with the more optimistic prognosis, it required some thought, she still did not want to live." More generally V was clear in her evidence that C "repeatedly told us that she didn't care whether her kidneys improved or not, and that she had thought about it, and that she wanted to die regardless. She – in the full knowledge that it was entirely possible that she might make a full recovery - said that if her kidney function improved, and she were discharged, that she would 'throw [herself] under a train'". No party sought to suggest that V was mistaken in her recollection of these conversations. On 10 November 2015 C told Dr Stevens that "I know that I could get better; I know that I could live without a health problem, but I don't want it". Dr Stevens states in his report that she "made very clear to me that she understands and has retained the information that her liver is making a good recovery and that her kidneys are recovering, albeit more slowly, such that her doctors wish her to undergo thrice weekly haemodialysis for some months to come. C also understands and has retained the information that her doctors expect her kidney function to recover such that haemodialysis can be discontinued at some point in 2016 and that her medical quality of life can be expected to improve thereafter." Whilst there are difficulties with Dr Stevens' report overall, I am prepared to accept that his recording of what C said to him is accurate, and indeed no party suggested otherwise.

- 80. I of course accept that there have been a number of occasions where C has appeared to reject out of hand her positive prognosis, in particular in conversations with Dr R on 29 September, 20 October, 3 November, 5 November, 9 November and 10 November 2015.
- However, in my judgment it is important to place these statements by C in their 81. proper context. In particular, they must be placed in the context of the other occasions, as summarised in the preceding paragraphs, when C has acknowledged her positive prognosis and weighed the same either tacitly or expressly. Thus, for example, whilst Dr R considered that on 29 September 2015 C was compromised by "very rigid thinking style and her distorted cognition such as black and white thinking and catastrophic thinking e.g. that she will forever require dialysis and will never recover to a stage where she can live an independent life again", as I have noted, on the same day C was recorded by Dr O as being clear in her understanding that without dialysis, adequate nutrition and treatment of her liver she would die and, within that context, as being able to take in the medical advice and fully understood the risk of refusing treatment. Further, C was recorded as appearing to have capacity on that date. Likewise, whilst telling Dr R on 10 November that "there is no hope 'a tiny sliver of hope' as she put it today, that she will get better" she told Dr Stevens on the same day that "I know that I could get better; I know that I could live without a health problem." In this regard I recall G's evidence that her mother's response to professionals will, in G's experience, depend on whether she considers them to be 'on her side' (part of her 'charm team' as C styles that group) or not and that Dr R was not considered to be part of that 'team'.
- 82. Further, in my judgment C's more categorical statements regarding her prognosis, and the question of the extent to which they demonstrate an inability to use and weigh

- information regarding the same, must also be placed in the context of the information that she was receiving during this period with respect to that prognosis.
- 83. Central to both the opinion of Dr R and the opinion of Professor P that C lacks the ability to use and weigh information relevant to her decision is C's alleged rigid and insistent rejection of her prognosis within the context of consistent optimism in this regard expressed by her treating doctors, characterised by Dr L's statement on 9 November 2015 that C's prognosis "remains excellent with survival fully anticipated". However, I am not satisfied that the medical records bear out the assertion that C was, in fact, receiving uniformly positive and reassuring information concerning her prognosis (most especially in relation to the likelihood of her being able to live a life without dialysis).
- 84. At the time C was said to have "an overvalued idea that her quality of life will not improve" on 25 September 2015 and at the time she refused dialysis on 29 September 2015, according to her medical records by that date she had, at best, received a guarded opinion to the effect that her prognosis was uncertain. When on 20 October 2015 C is recorded as stating that she does not want a life dependent on dialysis and of poor quality and apparently dismisses the medical opinion that she has every chance of making a good recovery and leading a fulfilling and normal life, she had the day before been told by Dr V only that there was a "possibility she may" get better and a "possibility she could" return to a degree of normality. Whilst On 3 November 2015, when C again refused dialysis, Dr R was concerned that the main driver of C's decision appeared to be her categoric belief that the timescale given to her for recovery had passed and that C considered that this meant she would not recover and did not want a lifetime of dialysis, the day before C had been told by Dr N that that no-one could predict how long it would take to recover and no one could tell for sure to what level of function she would recover. On 5 November, when Dr R was concerned that C was stating that "she believes she has no hope of recovery as she is now through the period of expected recovery as described to her. She is unflinching in her belief about this", according to the medical records Dr L appears to have told C that dialysis may not be a permanent situation and Dr S confirmed to C that there was no evidence of recovery so far and, accordingly, the prognosis was still unpredictable and remained uncertain even if the damage was potentially reversible.
- 85. Having regard to the foregoing summary, it is clear from the medical records that C was, entirely understandably, not receiving uniformly positive and reassuring information concerning her prognosis, both generally and in relation to the likelihood of her being able to live a life without dialysis. Whilst it is the case that on occasion C received a very positive assessment of her prognosis *after* incidents of refusing treatment (for example on 29 September 2015, on 21 October 2015, when Professor G explained in the presence of C that "we feel that the patient should get better very soon and that they [her kidneys] could improve any day now" and on 3 November 2015, when Professor G told C that her prognosis was good and that she could "be out with a drink in your hand by Christmas) it is not in my judgment accurate to characterise the prognosis C was being given as consistently positive. Her more categoric responses in respect of her prognosis must in my judgment be seen in this context when determining whether they are probative of an inability to use and weigh her prognosis in her decision making.

- 86. Further, in my judgment it is also important in this case not to confuse a decision by C to give no weight to her prognosis having weighed it with an inability on her part to use and weigh that information.
- It is clear that on occasions C's has expressed herself in terms of categorically 87. rejecting her prognosis in a way which gives the impression that she does not believe or accept that prognosis. However, on other occasions it is clear that her rejection of her prognosis is the result of her having considered it and given it no weight as against other factors more important to her. Thus, on 9 November 2015 C told Dr R that she knew what the doctors were doing and were not angry with them, as they were just trying to save her life but she did not wish to be saved. As I have noted, C told Dr Stevens on 10 November 2015 that "I know that I could get better; I know that I could live without a health problem, but I don't want it" and that "she had thought a great deal about her medical condition and that, despite appreciating that she has been given a good prognosis, she remains steadfastly determined to die as soon as possible." Later she told the representative from the Official Solicitor that "They are doing their best to do everything they can for me and unfortunately that is not what I want" and "I know they need to save lives. But I've chosen a different route." As noted, V recalls C telling her on a number of occasions that "she didn't care whether her kidneys improved or not, and that she had thought about it, and that she wanted to die regardless."
- 88. In my judgment these exchanges, and some of those outlined further above, are more consistent with C acknowledging her prognosis and choosing to give it no weight as against other information within the context of her own values and outlook when making a decision than they are with her failing to believe or weigh her prognosis when making her decision.
- 89. Finally, and within this context, in assessing whether C does have the ability to use and weigh information relevant to the decision in question it is also in my judgment very important to have regard to the fact that, in addition to the position C has taken with regard to her prognosis, she has given a range of reasons for reaching the decision she has regarding further treatment. C has, on a number of occasions, given very clear reasons for not wishing to continue her treatment. These reasons include the risk of a life lived on dialysis, the risk of long term disability, exhaustion with treatment and her wish not to endure further weeks or months of the same, her wish not to continue to endure the symptoms and pain associated with treatment, the risk she will not be able to attain her former lifestyle, her desire not to get old and lose her appearance and her wish to attain her original goal of ending her life.
- 90. Within this context I note in particular that it is clear from the medical records that C had and has a consistent and specific fear of having to live the rest of her life on dialysis. This expressed fear on the part of C is evident in her medical records. On 22 September 2015 C is recorded as *continuing* to state that, whilst hopeful of recovery, if her kidneys do not recover and she requires dialysis for the rest of her life she will not wish to live. C repeated this view on 23 September 2015. On 2 November C stated that she could not imagine herself dependent on dialysis and that it would be pointless to continue if she could not recover to a functional level where she could continue with her previous lifestyle. I pause to note that, in the context of the information given to C regarding her prognosis as summarised in Paragraphs 83 to 85 above, these fears on the part of C cannot be considered irrational.

- 91. Within the foregoing context, I am satisfied that it is not the case that C has undertaken the decision making exercise in relation to dialysis solely on the basis of a concrete or 'black and white' view taken in respect of her prognosis but rather on the basis of placing in the balance many factors relevant to the decision. That C considers that these factors outweigh a positive prognosis and the chance of life that it signals may not accord with the view that many may take in the same circumstances, and indeed may horrify some. However, they do in my judgment demonstrate C using and weighing information relevant to the decision in question when coming to that decision.
- 92. Having regard to the foregoing matters in my judgment the Trust has not proved to the requisite standard that C is *unable* to use and weigh information relevant to the decision in question such that she lacks capacity to make that decision. In circumstances where the Trust concedes that C meets the other criteria comprising the 'functional test' I am satisfied that C is not a person unable to make a decision for herself for the purposes of s 3(1) and, accordingly, does not lack capacity to decide whether or not to accept dialysis.
- 93. Having found that C is not a person unable to make a decision for herself for the purposes of s 3(1) it is not necessary for me to go on to consider the so called 'diagnostic test'. It is right to record that, as I observed at the conclusion of the hearing, had I been satisfied that C was unable to use and weigh information in the manner contended for by the Trust, I believe I would have had difficulty in deciding that this inability was, on the balance of probabilities, because of an impairment of, or a disturbance in the functioning of, the mind or brain. Whilst it is accepted by all parties that C has an impairment of, or a disturbance in the functioning of, the mind or brain, the evidence as to the precise nature of that impairment or disturbance was far from conclusive. Further, and more importantly, with regard to the question of causation, and in particular whether what was being seen might be the operation of a personality disorder or simply the thought processes of a strong willed, stubborn individual with unpalatable and highly egocentric views the evidence was likewise somewhat equivocal. However, as I say, I need say no more about this in light of my conclusions as set out above.
- 94. Finally, I of course bear in mind that my decision does not accord with the considered opinions of two very experienced psychiatrists. Whilst I have some concern that Dr R in particular set the test for capacity too high in this case in looking for C to demonstrate significant using and weighing of information demonstratively ending with a balanced, nuanced, used and weighed position, the fact that I have differed from Dr R and Professor P is in large part a product of this being a finely balanced case in which a number of reasonable interpretations of the information available are possible. In reaching my decision I must survey all the available evidence (see *PH v A Local Authority* [2011] EWHC 1704 (COP) at [16]). In the final analysis, and having had the benefit of surveying the entirety of the information available to the court I have come to a different interpretation of the finely balanced evidence to that favoured by the two psychiatrists, to both of whom I am grateful for their considered and extremely helpful evidence.

CONCLUSION

- 95. For the reasons set out above I am not satisfied on the evidence before the court that the Trust has established on the balance of probabilities that C lacks capacity to decide whether or not to accept treatment by way of dialysis.
- 96. Within the context of C's stated wish to refuse the life saving treatment which renal haemodalysis represents for her I am acutely conscious of the gravity of my decision. However, as set out at the beginning of this judgment, a capacitous individual is entitled to decide whether or not to accept treatment from his or her doctor. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient and, accordingly, a capacitous patient may refuse treatment even in circumstances where that refusal will lead to his or her death.
- 97. The decision C has reached to refuse dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, 'her sparkle' outweighs a prognosis that signals continued life will alarm and possibly horrify many, although I am satisfied that the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weigh heavily in the balance for C. C's decision is certainly one that does not accord with the expectations of many in society. Indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity. The court being satisfied that, in accordance with the provisions of the Mental Capacity Act 2005, C has capacity to decide whether or not to accept treatment C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.
- 98. In circumstances where I have decided that C has at this time the capacity to make the decision in question, this court has no jurisdiction to interfere with the decision making process. Accordingly, although rightly brought, I dismiss the application of the Trust for declarations under the Mental Capacity Act 2005.
- 99. As I said at the conclusion of this hearing, my decision that C has capacity to decide whether or not to accept dialysis does not, and should not prevent her treating doctors from continuing to seek to engage with C in an effort to persuade her of the benefits of receiving life saving treatment in accordance with their duty to C as their patient. My decision does no more than confirm that in law C is entitled to refuse the treatment offered to her for her benefit by her dedicated treating team. Nothing I have said prevents them from continuing to offer that treatment.
- 100. That is my judgment.