Neutral Citation Number: [2021] EWCOP 52

IN THE COURT OF PROTECTION
IN THE MATTER OF THE MENTAL CAPACITY ACT 2005

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22/09/2021

Before :

Mr Justice Poole

- -

Re PW (Jehovah's Witness: Validity of Advance Decision)

Between :

University Hospitals Birmingham NHS Foundation Trust	**Applicant**
- and –	
PW (By her Litigation Friend, the Official Solicitor)	**Respondent**

- -
- -

Ms Kohn (instructed by **Bevan Brittan LLP**) for the **Applicant Trust**
Ms Khalique QC (instructed by the **Official Solicitor**) for the **Respondent**
And **Ms W and Ms J,** daughters of PW**, appearing in person**

Hearing dates: Heard Out of Hours between 17-18 September 2021

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JUDGMENT

This judgment was delivered following an out of hours hearing conducted by telephone. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the respondent and members of her family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Poole:

Introduction

1. Mrs W has been a Jehovah's Witness for most of her adult life. She is now 80 years old and is in a perilous condition in hospital. She has severe anaemia following internal bleeding due to an ulcerated gastric tumour. The medical evidence to the court is that, in her current state and while the tumour remains, she is at risk at any time of sudden bleeding which if untreated would almost certainly end her life. With blood transfusion that immediate risk would be significantly reduced so that she would be able to undergo investigations and then surgical or possibly other treatment for her tumour and, given her general condition, she would be likely to survive the treatment and might live for another five to ten years.

2. An adult who has capacity to make a decision about receiving blood transfusion and who found themselves in Mrs W's position, could refuse blood transfusion and their decision would have to be respected, even if the decision were likely to have fatal consequences. Likewise, by s.26 of the Mental Capacity Act 2005 (MCA 2005), when a person who has lost capacity to make a decision about blood transfusion has previously made an advance decision which meets the requirements of the Act, is applicable to the treatment, and which remains valid, the advance decision has effect as if she had made it and had had capacity to make it at the time when the question arises whether the treatment should be carried out.

3. Mrs W is the respondent, PW, to this application made by University Hospitals Birmingham NHS Foundation Trust, the Trust responsible for the hospital where Mrs W is currently being treated. Mrs W has Alzheimer's dementia. Assessment by a Consultant Geriatrician at the hospital has concluded that she lacks capacity to make decisions about her treatment. However, enquiries made by a doctor at the hospital revealed the existence of an advance decision made by Mrs W in 2001 which appears to have been held on a register of such decisions made by Jehovah's Witnesses. Mrs W's advance decision clearly includes a decision to refuse blood or blood products even if her life is in danger. All parties accept that the advance decision was properly made and is applicable to the decision whether to refuse or consent to blood transfusion. The question for the court, if Mrs W lacks capacity to make a decision whether to consent to or refuse blood transfusion, is whether the advance decision is valid within the meaning of the MCA 2005. If it is, then her decision must be respected even though she may well die as a consequence. If it is not valid, and she lacks capacity to make the decision, then the court is required to assess what decision should be made on her behalf, in her best interests.

4. Under s.25(2) of the MCA 2005, an advance decision is not valid if the person who made it has withdrawn it, subsequently conferred authority on a donee or donees under a Lasting Power of Attorney to give or refuse consent to the treatment to which the advance decision relates, or if the person,

   "… (c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision."

5. There is no evidence that Mrs W remembers making the advance decision but there is no evidence that she has withdrawn it. In 2020 Mrs W donated Lasting Power of Attorney (LPA) to her four children appointing them to make decisions about her health and welfare on her behalf. This was registered with the Office of the Public Guardian. She did not give any specific instructions to the attorneys about treatment with blood transfusion or anything else, but she elected not to give her attorneys authority to give or refuse consent to life-sustaining treatment on her behalf.

6. When her capacity to make decisions about her medical treatment was being assessed in hospital, Mrs W expressed her agreement to having a blood transfusion. Thirty minutes later she said that she did not consent. The Trust relies on this as being clearly inconsistent with the advance decision remaining Mrs W's fixed decision. The Trust contends that her statements and actions render the advance decision invalid pursuant to s.25(2)(c) of the MCA 2005.

7. The key issues for the court to determine are:

    a. Does Mrs W have capacity to refuse or consent to blood transfusion?
    b. If she lacks capacity in that respect, is her advance decision to refuse blood transfusion valid?
    c. If she lacks capacity to refuse or consent to blood transfusion and her advance decision is invalid, is it in her best interests to be administered blood transfusion?

8. I heard this application as the Out of Hours Business Judge in the Court of Protection. The application was made in the evening of 17 September 2021. The hearing was conducted by telephone between 11.45 pm on 17 September 2021 and 3.25 am on 18 September 2021. I appointed the Official Solicitor to act as Mrs W's litigation friend. The Official Solicitor was represented by Ms Khalique QC. She and the Official Solicitor had very little time to prepare for the hearing. Ms W and Ms J, two of Mrs W's four children, attended and spoke on behalf of all the siblings. Mrs W is widowed and I was not made aware of any other significant family members. Ms Kohn represented the applicant Trust. I received witness statements and heard oral evidence from Mr A, Consultant Surgeon and Dr J, Consultant Geriatrician, from the Trust. I was provided with photographed copies of the advance decision and LPA, and notes recorded on computer by Dr J of his assessment of Mrs W. There was no other evidence. All parties proceeded on the basis that a determination had to be made with urgency given the extent of the risk to Mrs W and the consequences should such risk materialise.

9. At the conclusion of the hearing, I communicated my decision to the parties and said that I would provide a written judgment explaining my decision as soon as practicable. In short my decisions on the key issues are:

    a. Mrs W lacks capacity to refuse or consent to blood transfusion.
    b. Mrs W's advance decision is not valid.
    c. It is in Mrs W's best interests to undergo blood transfusion to restore and maintain her haemoglobin at or above 10 g/dl.

Due to the urgency of the out of hours hearing and the limited evidence available this judgment does not include a level of detail that would be expected following a longer court process.

Mrs W's Circumstances

10. The evidence establishes that Mrs W is 80 years old. She is a Jehovah's Witness. Her late husband was a very committed Jehovah's Witness. Her children believe that she joined the denomination to be a "good wife" to him but they also told me that she continued to attend meetings, including by a video link facility, until very recently when she went into a care home. Earlier this year, I was told by Ms W, her mother was admitted to hospital and it was noticed that a Do Not Resuscitate (DNR) notice had mistakenly been put in her medical records. Mrs W spoke to staff at the hospital to ensure that it was removed. I accept Ms W's assertion that at that time her mother did not raise the issue of being given blood.

11. Mrs W has Alzheimer's dementia. She also suffers from cardiomyopathy and hypertension and has been on aspirin. On 12 September 2021 she was admitted to the Trust's hospital vomiting blood. She was admitted to the surgical ward. A CT scan revealed what appeared to be a Gastro-intestinal stromal tumour (GIST). Endoscopy showed an ulcerated tumour in the fundus of her stomach. Mr A told me that Mrs W's haemoglobin on admission was 8.7 g/dl but fell to 5.0 g/dl on 15 September and was 5.1 g/dl on 17 September 2021. The normal range for a woman of Mrs W's age would be 12-15 g/dl. The initial level of 8.7 g/dl was indicative of anaemia but not sufficiently low to consider blood transfusion. Haemoglobin of 5.0 g/dl was indicative of severe anaemia and would normally prompt transfusion.

12. It was recorded in her hospital notes at some point after admission that she was a Jehovah's Witness. That may have been information given to medical or nursing personnel by Mrs W or by one of her family. Mr A's first involvement with Mrs W was on 17 September. He was however able to view the notes when giving evidence and reported to the court that on 16 September 2021 there had been a discussion with a haematologist who advised as to alternative supportive measures including EPO and iron. Mr A said that he would not expect a haematologist to have been contacted were it not for the fact that Mrs W was a Jehovah's Witness. Mr A told the court that the surgical team would decide whether blood transfusion was required without the need to confer with a haematologist. In his professional opinion there was an urgent need for blood to be given. He said,

> "While the tumour remains she is at risk of sudden and potentially catastrophic bleeding which could end her life if not treated. Although we have no evidence that the tumour is bleeding this could happen at any moment.
>
> "If a bleed were to happen she would almost certainly die. The risk of death can be reduced significantly by administration of a blood transfusion. This would also be part of preparation for

> surgical treatment by raising her haemoglobin level. Her current haemoglobin level means that surgery cannot be undertaken."

13. In his oral evidence to the court Mr A said that surgery was not the only option for treatment for the GIST. Once blood transfusion was given to protect her life, Mrs W would be investigated further. Histopathological samples would be reported. Malignancy would have to be excluded but Mr A thought malignancy was unlikely. There would be an option of injecting the ulcerated tumour with adrenaline, and other non-surgical options. A multi-disciplinary meeting would be held and discussions would take place with Mrs W and the family before determining the best course of treatment. Mrs W was generally in reasonable health and, after treatment of the ulcerated tumour, assuming investigations and screening scans were clear for malignancy, she could live for another five to ten years.

14. Mr A told the court that he understands that a junior doctor noticed that Mrs W was a Jehovah's Witness and contacted a database or register which held her advanced decision. This came to light only on 17 September 2021. Mrs W had told Mr A that she did not want a blood transfusion even after the risks associated with not having it were explained to her. In contrast, her children were anxious that she should have a transfusion. Mr A believed that it was in her best interests to have a blood transfusion given the significant risks to her of not having a transfusion, and the minimal intervention and risk involved in giving a transfusion.

Assessment by Dr J

15. Mr A asked for Mrs W to be assessed for her capacity to refuse or consent to treatment. She was first seen on 17 September by Dr C, a Consultant Geriatrician. I have no statement from Dr C and no notes of her assessment. Dr J, who gave evidence to the court, told me that he had spoken to Dr C after his own assessment, but not before it, and she told him that Mrs W had declined blood transfusion but that she was uncertain whether or not she had capacity to make that decision.

16. Dr J, Consultant Geriatrician, first saw Mrs W at 1500 hrs on 17 September 2021. He recorded his interview with her as follows:

> "… she was alert, sat in the chair, subjectively comfortable.
>
> Nursing staff report she is calm, mobile around the ward to toilet, compliant with care and medications.
>
> There is no evidence she has a reversible cognitive impairment such as delirium.
>
> She is not on any medications that impair cognition or decision making."

Dr J told me that, contrary to a comment in his written statement, he does not think that Mrs W's severe anaemia contributed to her low cognition (as later described). His note continues,

> "She could not recall why she was in hospital or what had been found. She could not recall this either when prompting about the OGD [Oesophago-Gastro-Duodenoscopy – one of the investigations she had undergone] and a 'mass in the stomach'.
>
> She could not recall any previous conversations about blood transfusions.
>
> I asked her if she would have a blood transfusion – 'I'd have to think about it.' I asked if she would have a blood transfusion if it meant this would save her life, and not having it may cause her to die – 'in that case I would have it, if it was clean blood'. 'What do you mean by 'clean' blood?'; 'Blood free from diseases'.
>
> When I said she had told other people she had refused blood in all situations she said, 'maybe I did, I can't remember.'
>
> She kept saying that she was tired and asking how long she had been 'here'. She was often surprised when I told her she was in hospital."

17. Dr J struck me as a careful and considered witness and an experienced clinician who sensibly returned to Mrs W 30 minutes after the conclusion of his first interview with her. On this occasion he noted that she recalled that they had talked about an operation but nothing else.

> "On prompting about blood transfusions she said 'I won't have a blood transfusion'. On saying that she would die without a blood transfusion, she repeated, 'In that case, I'll die.'
>
> 'Why can't I have tablets' – 'they would work quickly enough'… 'in that case I'll die'.
>
> I said her family wanted her to have a blood transfusion and didn't want her to die. 'that is their decision.'
>
> I said that letting her die would be a very difficult decision, 'I have made my peace with Jehovah and will talk to him then.'
>
> After 5 minutes I asked 'what would happen if you refused a blood transfusion?' She answered 'I will die.'"

18. Dr J wrote up his conclusions at the time:

> "This is not an easy situation, and her mild cognitive impairment/dementia makes things feel harder. In our first conversation I would feel she lacks capacity at that time to make complex health related decisions due to dementia and severe anaemia. I don't think she could retain and weigh up information.
>
> Our second conversation was different however, and she gave a clear rationale for refusing, understood the consequences (death) and was consistent with this.
>
> We should always assume capacity and in this case her capacity is fluctuant so on balance I would say she does have capacity to refuse a blood transfusion even in a life threatening situation."

Dr J raised questions about the urgency of the need for an operation and whether there was a valid advance decision to refuse treatment: "I understand the team is on the case". He proposed continuing to assess capacity and ended his note with, "Sorry I cannot be more definitive."

19. Dr J then prepared a statement for the court's assistance and gave oral evidence. He told me that he had had time to reflect further before making his statement and had reached a different conclusion. He says in his statement:

> "I do not believe that Mrs W is capable of making a decision about accepting or refusing a transfusion. When I spoke to her she was not orientated to time and place. She could not remember previous discussions about her care and treatment. She was unable to say why she was in hospital; she could not recall earlier conversations with me and was not able to weigh up information given to her…
>
> At one point she told me that she would accept a transfusion provided she was given 'clean' blood by which she meant uncontaminated blood. She did not say that she would refuse blood simply because it was from another person and was not her own. A few minutes later she told me that she would not accept blood, although my impression was that she was reciting reasons rather than expressing a genuinely held opinion."

20. Dr J expanded significantly on this analysis in his oral evidence. He told me that he had reflected further and that whilst it could have been said that superficially Mrs W had capacity to refuse treatment, she was actually unable to discuss the reasons behind her responses. Her answers in the second interview were formulaic. He accepted a description of some dementia sufferers masking their inability to reason and process information by resorting to formulaic sayings which are a comfort to them. I understood his evidence to be that this was how he now viewed Mrs W's presentation at their second interview. In contrast, in the first interview her answers were not stereotyped and there was a degree of thought process involved.

21. Dr J had not seen the advance decision when he saw Mrs W. She did not mention it at any stage, nor did she tell him she was a Jehovah's witness (although she did refer to Jehovah (see notes above)). In his written statement, Dr J said this about the advance decision:

> "I do not believe that she genuinely still believes in what she wrote many years ago. Her answers to my questions were formulaic and did not seem to reflect her real wishes. Her answers were also not consistent. I recognise that this assumption is based on a single meeting with her and I do not have enough information about her to suggest that her Advance Decision is no longer valid. At one point today, however, it did not appear to reflect her wishes and feelings."

Dr J's evidence to the court about capacity conflicted with his initial impression as recorded in his notes. However, he explained that he had changed his opinion after reflection and he gave full reasons for his change of mind. He was a careful witness whose oral evidence to the court I found to be reliable.

Advance Decision and LPA

22. The advance decision was signed by Mrs W on 29 November 2001. It was headed, "advance directive" but I shall refer to it as an advance decision which is the term now used under the MCA 2005. The opening paragraph ends, "It will remain in force unless and until specifically revoked in writing by me." It is witnessed by two witnesses. It is three pages long and includes the following (capitalisation as in the original document):

> "I am one of Jehovah's Witnesses. On the basis of my firmly held religious convictions … and on the basis of my desire to avoid the numerous hazards and complications of blood transfusions, I absolutely REFUSE allogeneic blood (another person's blood): the primary blood components red cells, white cells, platelets and/or plasma; and stored (predonated) autologous blood (my own stored blood) under any and all circumstances, no matter what the consequences.
>
> MY DECISION to refuse blood and choose non-blood management MUST BE RESPECTED EVEN IF MY LIFE OR HEALTH IS THREATENED by my refusal. Any attempt to administer blood contrary to my instructions will be a violation of my rights of bodily self-determination and personal autonomy, and accordingly will constitute an actional trespass to my person."

The whole of the second paragraph in the extract above, and much of the first, were printed in bold lettering. Mrs W had ticked rather than initialled certain choices within the advance decision. She seems then to have initialled the options and added her surname to the initials – a second copy of the advance decision was produced showing

those changes. It appears that she added her initials on the same date as she signed the document: 29 November 2001. Amongst the options she initialled was "I refuse all fractions derived from any primary component of blood." There is a section within the advance decision which includes options with regard to "end-of-life decisions".

23. Having regard to s.4(10) of the MCA 2005 (see below), and Mr A's evidence, I proceed on the basis that blood transfusion administered now to Mrs W should be regarded as "life-sustaining treatment". The decision about blood transfusion in this case is not, however, an end-of-life decision. The current evidence is that Mrs W has an acute condition which would, under normal circumstances, not be likely to end her life. She is not in the late stages of a terminal illness.

24. There are different elements to the advance decision but the refusal of allogeneic blood is very clearly stated to apply "under any and all circumstances". That advance decision is applicable to the administration of allogeneic blood or blood products as life-sustaining treatment but it is not restricted to life-sustaining treatment.

25. Although it was made before the MCA 2005 came into force, the advance decision complies with the requirements for making an advance decision to refuse life-sustaining treatment (see s.25 of the MCA 2005). It is in writing, signed in the presence of witnesses, it includes a clear, specific written statement that it is to apply to the specific treatment – the administration of blood – even if life is at risk. There is no evidence that Mrs W took advice from a healthcare professional at the time that she made the advance decision but that was not and is not a requirement for the advance decision to be effective.

26. Mrs W has not withdrawn the advance decision but neither has she renewed or updated it since 2001. Paragraph 9.29 of the Mental Capacity Act Code of Practice states that,

> "Anyone who has made an advance decision is advised to regularly review and update it as necessary. Decisions made a long time in advance are not automatically invalid or inapplicable, but they may raise doubts when deciding whether they are valid and applicable. A written decision that is regularly reviewed is more likely to be valid and applicable to current circumstances…"

27. The LPA was signed by Mrs W on 10 August 2020. The certificate provider has properly signed the document and Mrs W's four children are named as attorneys. All signatures are properly witnessed. The LPA is stamped as validated and was registered by the Office of the Public Guardian on 27 November 2020. The certificate provider has signed to confirm that they have discussed the LPA with the donor and that the donor "understands what they're doing and that nobody is forcing them to do it." The certificate provider must be someone who has known the donor personally for at least 2 years or someone with relevant professional skills, such as the donor's GP, a healthcare professional, or a solicitor. The LPA gives the attorneys authority to make decisions about Mrs W's health and welfare when she cannot act for herself because she lacks mental capacity, subject to the terms of the LPA and the provisions of the MCA 2005.

28. The LPA form includes a section headed "Preferences and Instructions" allowing the donor to tell her attorneys how she would prefer them to make decisions or to give specific instructions which they must follow when making decisions. The standard form states, "Most people leave this page blank – you can just talk to your attorneys so they understand how you want them to make decisions for you." Mrs W did not include any preferences or instructions. As noted below, her children say that she told them she would like to be resuscitated if the need arose but did not tell them of any other preferences or instructions. She did not tell them that she had made an advance decision.

29. The LPA also includes a section headed "Life-sustaining treatment". The instruction is headed "This is an important part of your LPA" and states:

> "You must choose whether your attorneys can give or refuse consent to life-sustaining treatment on your behalf. Life sustaining- treatment means care, surgery, medicine or other help from doctors that's needed to keep you alive, for example:
>
> A serious operation, such as a heart bypass or organ transplant
>
> Cancer treatment
>
> Artificial nutrition or hydration (food or water given other than by mouth)
>
> Whether some treatments are life-sustaining depends on the situation. If you had pneumonia, a simple course of antibiotics could be life-sustaining."

Mrs W opted not to give her attorneys authority to give or refuse consent to life-sustaining treatment on her behalf.

The Family's Views

30. I heard from Mrs W's daughters, Ms W and Ms J, who spoke on behalf of their other two siblings at the hearing. Mrs W is widowed and there are no other significant family members so far as I am aware. There is no question that the children love their mother dearly but no disguising the hostility they feel towards the Jehovah's Witnesses denomination. They feel that their mother was pressurised into making her advance decision and was indoctrinated. Their father, Mrs W's late husband, was a committed Jehovah's Witness, and Mrs W went along with him because she is a "person who likes to please" and wanted to be a "good wife". They felt that Mrs W was now being treated as "disposable" and that the idea that she should not be given a blood transfusion was akin to euthanasia. They were convinced that she wants to live and would choose to have a blood transfusion if she were able to give a considered and clear view.

31. Mrs W's children told me that when the LPA was prepared and signed, Mrs W did not mention the advance decision and said to them that she would like to be resuscitated (although she did tick Option B, removing decisions about life-sustaining treatment

from her attorneys' authority). Earlier this year Mrs W was very ill in hospital and was very clear that she wished to be resuscitated if the need arose. A "DNR" order had been mistakenly included in her medical notes and she insisted on it being removed. The children told me, through Ms W, that Mrs W had never mentioned the advance decision to them and they had been completely unaware of its existence.

The Law

Capacity

32. The key provisions of the MCA 2005 which the court must follow when determining an issue of capacity are set out at sections 1 to 3:

"**1 The principles**

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."

33. I adopt the guidance of the Vice President Mr Justice Hayden in *London Borough of Tower Hamlets v PB* [2020] EWCOP 3 and MacDonald J in *Kings College Hospital NHS Foundation Trust v C and V* [2015] EWCOP 80 at paragraphs 25 to 39. I bear in mind that it would be unfair to set the bar too high - *Sheffield City Council v E* [2004] EWHC 2808, para. 144 per Munby J, as applied by Baker J in *PH v A Local Authority* [2011] EWHC 1704]. A linked principle is that the person must understand the salient information but not necessarily all the peripheral detail: *LBC v RYJ* [2010] EWHC 2665.

Advance Decisions

34. The law on advance directives is set out in ss.24 to 26 of the Mental Capacity Act 2005:

24 Advance decisions to refuse treatment: general

(1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if–

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment,

the specified treatment is not to be carried out or continued.

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

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

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

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

25 Validity and applicability of advance decisions

(1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time–

(a) valid, and

(b) applicable to the treatment.

(2) An advance decision is not valid if P–

(a) has withdrawn the decision at a time when he had capacity to do so,

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.

(4) An advance decision is not applicable to the treatment in question if–

(a) that treatment is not the treatment specified in the advance decision,

(b) any circumstances specified in the advance decision are absent, or

(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

(5) An advance decision is not applicable to life-sustaining treatment unless–

(a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and

(b) the decision and statement comply with subsection (6).

(6) A decision or statement complies with this subsection only if–

(a) it is in writing,

(b) it is signed by P or by another person in P's presence and by P's direction,

(c) the signature is made or acknowledged by P in the presence of a witness, and

(d) the witness signs it, or acknowledges his signature, in P's presence.

(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

26 Effect of advance decisions

(1) If P has made an advance decision which is–

(a) valid, and

(b) applicable to a treatment,

> the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.
>
> (2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.
>
> (3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.
>
> (4) The court may make a declaration as to whether an advance decision–
>
> (a) exists;
>
> (b) is valid;
>
> (c) is applicable to a treatment.
>
> (5) Nothing in an apparent advance decision stops a person–
>
> (a) providing life-sustaining treatment, or
>
> (b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition,
>
> while a decision as respects any relevant issue is sought from the court."

35. Important guidance is set out in Chapter 9 of the Mental Capacity Act Code of Practice as endorsed by the court in *X Primary Care Trust v XB* [2012] EWHC 1390 Fam.

36. A person who has capacity is not at all bound by their advance decision. They have capacity to refuse or consent to treatment as they choose, irrespective of what advance decisions they have made. The applicability and validity of an advance decision become relevant only when a person who has made an advance decision now lacks capacity in relation to a decision about treatment. It is clear that if an applicable and valid advance decision exists and is being followed, then the best interests principle does not apply. If, on the other hand, the advance decision is either not applicable or not valid, or both, then refusal or consent to treatment is a decision which must be made on their behalf in their best interests.

<u>Best interests</u>

37. Section 4 of the MCA 2005 governs the assessment of a person's 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.

38. The Code of Practice states:

> "5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.

> 5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.
>
> 5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests."

39. In *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, Lady Hale said at [39]:

> "In considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

And at [45]:

> "The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which

> were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.”

40. Mrs W’s human rights under Articles 2 (right to life), 3 (protection from inhuman or degrading treatment), 8 (right to respect for a private and family life), and 9 (freedom of thought, conscience and religion) of the European Convention on Human Rights are engaged. It has been recognised by the European Court of Human Rights that there is a presumption strongly in favour of prolonging life where possible.

Submissions

41. Ms Kohn for the Applicant Trust submitted that Mrs W lacked capacity to make a decision about treatment by way of blood transfusion and that the evidence established that Mrs W had acted in a way clearly inconsistent with the advance decision being her fixed decision. She submitted that it was in Mrs W’s best interests to undergo blood transfusion. Initially the Trust sought declarations in relation to Mrs W undergoing surgery, but by closing submissions it was clear that any decision as to whether surgery or some non-surgical treatment would be recommended was some days away. The urgent need was for a blood transfusion.

42. Ms W and Ms J on behalf of the family told the court that their mother was not able to make such decisions for herself because of her dementia, but that they were sure that she wanted to live and to be treated so as to allow her to survive this acute medical episode. They considered that it was without doubt in her best interests to undergo transfusion.

43. For the Official Solicitor, acting on behalf of Mrs W, Ms Khalique QC focused her sensitively made submissions on the advance decision. She emphasised that whatever the views of her children, Mrs W had remained a Jehovah’s Witness for many years. She had continued to attend meetings, even by video conferencing during the Covid-19 pandemic, until very recently. She had not withdrawn the advance decision. It ought to be respected and her autonomy should not be overridden. S.25(2)(c) required acts to be “clearly” inconsistent with the advance decision remaining Mrs W’s fixed decision, and the evidence did not reach that standard.

Conclusions

44. I could have delayed making determinations about the key issues in this application. It would have been possible to seek a further assessment of Mrs W’s capacity on 18 or 19 September and direct further disclosure of her medical records, further evidence from family members, and allowed further time for the Official Solicitor to meet Mrs W and potentially to obtain further relevant evidence regarding her advance decision, wishes and feelings. However, no party sought an adjournment and in any event I was presented with compelling evidence that Mrs W required a blood transition urgently and was at risk of dying due to complications which could occur “at any time” if she

were not given a blood transfusion. I was told that clinicians were "standing by" ready to give blood if so authorised. It would, in my judgement, have been an abrogation of responsibility not to make a decision on the evidence before me. With the considerable assistance of counsel, the court did its best to extract and scrutinise the evidence available in order to make the best informed decision that could be made in the circumstances.

Capacity

45. I found Dr J's evidence to be persuasive. He advised the court that Mrs W lacked capacity to make a decision about accepting or refusing a transfusion. His evidence demonstrated that Mrs W was unable to retain relevant information for a sufficient time necessary for her to make this important decision. She was not aware of, and so did not understand, salient information such as the nature and seriousness of her medical condition or that it gave rise to the clinical need for blood transfusion. She could not, Dr J advised, weigh or use relevant information given to her. Dr J advised that Mrs W has Alzheimer's dementia. He considered whether other factors such as low haemoglobin were affecting her ability to make the decision in question, but in his oral evidence to the court he made it clear that her inability to make the decision was because of her dementia. Her dementia is an impairment of, or a disturbance in the functioning of, the mind or brain. There is a presumption of capacity and I bear in mind that Dr J's colleague and, initially Dr J himself, did not believe that this was a clear case of lack of capacity to make the decision about blood transfusion. However, after time for reflection, Dr J gave clear evidence to the court that in his opinion Mrs W was unable to make such a decision because of her dementia. The family agreed. No other evidence before me suggested that Dr J's evidence was wrong. I acknowledge that the Official Solicitor has not had an opportunity to meet Mrs W. However, on the evidence before the court I am satisfied that on the balance of probabilities Mrs W lacks capacity to make a decision to refuse or consent to blood transfusion.

46. The test for capacity to conduct litigation is found in *Masterman-Lister v Jewell* [2002] EWCA Civ 189. On the evidence produced to the court is it clear to me that Mrs W lacks capacity to conduct litigation. Accordingly, I directed that the Official Solicitor should be appointed litigation friend to act on Mrs W's behalf.

Advance Decision

47. There is no dispute that the advance decision made by Mrs W in 2001 meets the requirements subsequently set out in the MCA 2005 and MCA Code of Practice. Those requirements came into force on 1 October 2007. An advance decision made before then remains valid if it meets the requirements. Mrs W has not reviewed her advance decision after 2007 but it meets the requirements in any event. I am also satisfied that it is applicable to the treatment being considered. It has not been withdrawn and the LPA made in 2020 did not confer authority on the donees to give or refuse consent to blood transfusion as life-sustaining treatment. I am satisfied that in the circumstances that currently prevail, I should regard the proposed blood transfusion as "life-sustaining treatment." Accordingly, the court's focus is on whether, in accordance with s.25(2)(c) of the MCA 2005, the advance decision is no longer valid because Mrs W

has "done anything else clearly inconsistent with the advance decision remaining her fixed decision."

48. In seeking to apply s.25(2)(c) to the facts of the present case, the court is not bringing into conflict what Hayden J in *LB of Tower Hamlets v PB* [2020] EWCOP 34 referred to as the "healthy and moral human instinct to protect vulnerable people" with the principle of autonomy. Rather, anxious scrutiny of whether an advance decision remains valid is necessary to ensure that the person's autonomy is protected. In his pre-MCA 2005 judgment, *HE v A Hospital NHS Trust* [2003] EWHC 2017 (Fam), Munby J said at [37],

> "In my judgement it is fundamental that an advance directive is, of its very essence and nature, inherently revocable. An irrevocable advance directive is a contradiction in terms and is, in my judgment, a legal impossibility. An advance directive is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination. A free man can no more sign away his life by executing an irrevocable advance directive refusing life-saving treatment than he can sign away his liberty by subjecting himself to slavery. Any condition in an advance directive purporting to make it irrevocable is contrary to public policy and void."

49. Munby J's articulation of the principle involved survives the introduction of the MCA 2005 but subsequent paragraph of his judgment has to be read in the light of the "new" statutory provisions:

> "[39] It is, of course, clear that when a previously competent adult patient loses both his capacity to decide whether or not to accept medical treatment and any ability to express his wishes and feelings then a previously valid advance directive that has not been revoked in the meantime will in effect become and, at least as long as the patient continues in that condition, will in effect remain irrevocable. But this is not because the advance directive as such either is or has become irrevocable – it has not. It is simply because there is now no-one who is able to revoke it. Only the patient himself can revoke his own advance directive. That is inherent in the very concept of an advance directive – which is, as I have said, the embodiment of the patient's autonomy and his right of self-determination. And in the situation postulated the patient no longer has the capacity to revoke his advance directive."

50. Under s.26 of the MCA 2005, an advance decision only has effect when the person who made it has subsequently lost capacity to make the material decision. The advance decision can be withdrawn (s.25(2)(a)) or displaced by an LPA (s.25(2)(b)) but withdrawal can be effected and an LPA can be granted only when the person concerned has capacity to do so. No such restriction applies to s.25(2)(c). I interpret s.25(2)(c) as allowing for the advance decision to be rendered not valid should the person who made

the advance decision do “anything else” (other than withdrawal or granting an LPA which displaces the advance decision) which is “clearly inconsistent” with the advance decision remaining their fixed decision, before or after they have lost capacity to make the relevant treatment in question. The question will only arise after they have lost capacity but the court may consider things done before or after that time. Munby J refers to a person being locked into their advance decision once they have lost both capacity to decide whether or not to accept medical treatment and any ability to express their wishes and feelings. Similarly, s.25(2)(c) allows for a person who has lost capacity nevertheless to do something or to have done something which renders the advance decision not valid.

51. I also note that s.25(2)(c) will only fall to be considered in the case of a person who has not withdrawn (revoked) their advance decision, and who has not subsequently granted an LPA conferring authority to give or refuse consent to treatment to which the advance decision relates. Something other that express withdrawal of the advance decision may suffice to render it not valid. It follows that, as Munby J emphasised in *HE v A Hospital NHS Trust* (above), the term within Mrs W’s advance decision that “It will remain in force unless and until specifically revoked in writing by me” is unenforceable.

52. Three words within s. 25(2)(c) require particular comment:

    a. “done”: I read this to include words as well as actions. I am strongly reinforced in this view by what Munby said at paragraph [43] of his judgment in *HE v A Hospital NHS Trust* (above):

    > “No doubt there is a practical – what lawyers would call an evidential – burden on those who assert that an undisputed advance directive is for some reason no longer operative, a burden requiring them to point to something indicating that this is or may be so. It may be words said to have been written or spoken by the patient. It may be the patient’s actions – for sometimes actions speak louder than words. It may be some change in circumstances. Thus it may be alleged that the patient no longer professes the faith which underlay the advance directive.”

    The statutory provision does not refer to words and actions, only what P has “done”, but it would be an odd restriction on the interpretation of “done” to exclude written or spoken words when the provision is addressed to previous written or spoken words in the form of an advance decision (an advance decision about treatment which is not life-sustaining treatment may be made verbally).

    b. “clearly”: the court should not strain to find something done which is inconsistent with the advance decision remaining the individual’s fixed decision. Something done or said which could arguably be “inconsistent”, or which the court could only find might be inconsistent will not suffice.

c. "fixed": s.25(2)(c) does not merely require something done which is inconsistent with the advance decision, but rather something done which is inconsistent with it remaining the person's *fixed* decision. Fluctuating adherence to the advance decision may well be inconsistent with it remaining their fixed decision. As with the other elements of the test, whether it is inconsistent will depend on the facts of each case.

53. The Trust asserts that the advance decision is not now valid because s.25(2)(c) is made out. I treat the burden of proof as being on the Trust which must establish that on the balance of probabilities Mrs W has done something inconsistent with the advance decision remaining her fixed decision.

54. The following matters make it more difficult than otherwise to establish that Mrs W has done something clearly inconsistent with the advance decision remaining her fixed position:

    a. In 2001 Mrs W made a written, witnessed advance decision applicable to the proposed treatment with blood transfusion to save her life. She made it as a Jehovah's Witness and in accordance with her beliefs as a Jehovah's Witness.

    b. Mrs W has been a Jehovah's Witness for many years and has continued to attend meetings until very recently.

    c. The advance decision included very clear and robustly worded statements that Mrs W would refuse blood and blood products even if her life was threatened.

    d. There is no evidence before the court that Mrs W made the advance decision when under undue influence.

55. However, the following matters also provide relevant context in which to consider whether the advance decision remains Mrs W's fixed decision:

    a. In the twenty years since she made the advance decision, whilst she has not revoked or withdrawn it, Mrs W has not updated or reviewed it.

    b. The evidence from Mrs W's family is that Mrs W has never discussed the advance decision or its contents with them – they were unaware of its existence. However, I must take into account the disdain which Mrs W's children have for the denomination, which may have dissuaded Mrs W from discussing her advance decision with them.

56. The following further matters weigh in favour of a finding that Mrs W has done something clearly inconsistent with the advance decision remaining her fixed decision:

    a. Less than one year ago Mrs W made an LPA authorising her attorneys (her four children) to make all decisions about her health and welfare, save for refusal or consent to life-sustaining treatment, on her behalf. At that time, I must presume in the absence of any contrary evidence, she had capacity to grant LPA to her children. She knew that they were hostile to the denomination to which she belonged but she did not set out any preferences or instructions in her LPA.

Furthermore, as I accept, she did not tell her children that she had made an advance decision and did not request them not refuse blood transfusion or blood products on her behalf. Whilst her LPA did not give authorisation to her attorneys in respect of life-sustaining treatment, blood transfusion or blood products may be used as treatment other than to sustain life. The advance decision related to the use of allogeneic blood and blood components for any purpose. That does not appear to have been her decision when she made the LPA and therefore the granting of the LPA, in the circumstances of this case, is inconsistent with the advance decision remaining Mrs W's fixed decision.

b. I accept what I was told by Mrs W's daughters at the hearing, namely that at the time the LPA was signed, Mrs W told them that she would want to be resuscitated if necessary and that she did so without reference to her advance decision or her refusal to countenance receiving a blood transfusion as part of resuscitation. Further, earlier this year Mrs W wished for a "Do Not Resuscitate" notice to be removed from her medical notes and again did not qualify that wish by insisting that she should not receive blood transfusion as part of resuscitation.

c. Mrs W told Dr J at 1500 hrs on 17 September 2021, that she would have a blood transfusion if it meant it would save her life and not having it may cause her to die. Her only qualification was that it should be blood "free from diseases." I have carefully considered Dr J's evidence to the court about the conversation he had with Mrs W at that time, his subsequent conversation with her in which she said she would not have a blood transfusion, and his reflections on those discussions. I accept his characterisation of the discussions as expressed in his oral evidence: in the first discussion Mrs W appeared to be engaged in a form of thought process, avoiding formulaic language. In the second she seemed to resort to formulaic language and not to be engaged in any form of thought process.

d. Whilst I have found that Mrs W lacks capacity to refuse or consent to blood transfusion, I am satisfied that the evidence shows that she is still able to express her wishes and feelings about such treatment, albeit inconsistently and sometimes resorting to formulaic expressions.

e. I take into account Dr J's considered opinion, after reflection, that "I do not believe that she genuinely still believes in what she wrote many years ago [in the advance decision]." Dr J has had the benefit of speaking directly to Mrs W and his opinion must carry weight.

57. The determination of whether Mrs W has done something clearly inconsistent with the advance decision remaining her fixed decision has profound consequences and requires the most anxious consideration. I recognise that the evidence before me does not all go one way. However, weighing all the matters discussed, I am satisfied, on the balance of probabilities, that Mrs W has done things clearly inconsistent with the advance decision remaining her fixed decision. She granted to her children, whom she surely knew were hostile the Jehovah's Witnesses denomination, authority to make decisions about all medical treatment, other than life-sustaining treatment, on her

behalf should she lose capacity to make such decisions for herself, without mentioning to them or including in the written LPA any preference or requirement not to receive blood transfusion or blood products. The advance decision was widely drawn and did not restrict the refusal of consent to blood transfusion or blood products by way of life-sustaining treatment. Her actions at the time of granting the LPA were in my judgment clearly inconsistent with the advance decision remaining her fixed decision. For the reasons stated earlier, I must presume that she had capacity at that time.

58. Likewise, Ms W's actions earlier this year on requesting the removal of the DNR notice, without qualification and without telling her children or, to their knowledge, her clinicians, about the advance decision or that she would refuse a blood transfusion or blood products is, in my judgment inconsistent with the advance decision remaining her fixed decision.

59. Mrs W's stated wish at 1500 hours on 17 September 2021 to have transfusion of blood "free from diseases" if she might die without it, was an expression of wishes and feelings which were inconsistent with the advance decision remaining her fixed decision. Whilst she later expressed wishes and feelings which were consistent with her advance decision, the test under s.25(2)(c) requires the court to consider whether Mrs W has done anything clearly inconsistent with the advanced decision remaining her "fixed" decision. I find that when she expressed wishes and feelings inconsistent with the advance decision she was expressing genuine wishes and feelings with more clarity of thought than when she spoke with Dr J half an hour later. It would be open to the court to dismiss both, contradictory expressions of her wishes and feelings as having no weight because of her cognitive impairment. But I am satisfied that some weight should be given to what she said to Dr J, in particular in the first conversation when, in his considered view, she was not resorting to formulaic expressions. Even if equal weight were given to both, contradictory assertions of her wishes and feelings, it could hardly be said that Mrs W was acting consistently with the advanced decision being her "fixed" decision.

60. Taking all these matters together, I am satisfied that Mrs W has done things "clearly inconsistent with the advance decision remaining her fixed decision" and that pursuant to s.25(2)(c) of the MCA 2005 the advance decision is not valid.

61. No submission was made to me that s.25(2)(b) applied because the lasting power of attorney from 2020 conferred authority on the donees to give or refuse consent to the treatment to which the advance decision relates. Although the LPA expressly did not apply to decisions about life-sustaining treatment, and the treatment under consideration is life-sustaining treatment, the LPA surely conferred authority on the donees to give or refuse consent to the administration of allogeneic blood and blood products by way of non life-sustaining treatment. On the one hand, the advance decision relates to such treatment whether life-sustaining or otherwise but, on the other, the treatment which is now being considered is life-sustaining treatment for which authority was not granted. It might have been argued, but was not, that s.25(2)(b) is satisfied. Since this was not argued at the hearing and did not form the basis of the decision that I communicated at the hearing, I have not asked for further submissions on this issue and I make no determination as to whether s.25(2)(b) applies in this case.

Best Interests

62. I take into account all the circumstances and all the information and evidence before the court, in particular:

    a. Blood transfusion would be a relatively risk free procedure which does not involve a major physical invasion on Mrs W's person.

    b. The consequences of her not receiving blood transfusion would be to expose her to a very significant risk of death.

    c. The need for transfusion is very urgent.

    d. Blood transfusion is likely to be effective in preventing her from a fatal further bleed and allowing her to undergo further investigation and treatment for her ulcerated tumour. Following blood transfusion there is every chance that Mrs W could undergo treatment for her underlying condition which may allow her to live for a further five to ten years.

    e. The views of Mrs W's treating clinicians are strongly that she should undergo blood transfusion forthwith as being in her best interests.

    f. The views of Mrs W's family (as represented before me) are strongly that she should undergo blood transfusion without delay. They also firmly believe that their mother would choose to have a blood transfusion if she had capacity to make that choice. She wants to be kept alive. I have to allow for the hostility the children feel towards the Jehovah's Witnesses denomination and its influence over their mother, but I am satisfied that their view of what their mother would want, namely, to have blood transfusion if it meant that she might otherwise die, is a genuine view of their mother's own wishes and feelings at this stage of her life.

    g. Whilst Mrs W has been a Jehovah's Witness for most of her adult life and made an advance decision twenty years ago to refuse blood transfusion even if her life were under threat, I have to take into account the findings I have made that she has done things clearly inconsistent with that decision remaining her fixed decision. Further, she has not mentioned the advance decision to her family or to any of the clinicians now treating her. Very recently, whilst suffering from Alzheimer's dementia and lacking capacity to make decisions about blood transfusion, she has expressed contradictory views about receiving blood transfusion. She appeared to have more clarity of thought when saying that she would have blood transfusion if it was to save her life. It is difficult to ascertain her current wishes and feelings but I conclude that if she had capacity, she would not now adhere, at least not with commitment and consistency, to the tenets of Jehovah's Witnesses regarding blood, as she appears to have done two decades ago when she made her advance decision. Her wish to live is stronger than any residual beliefs that she should not receive blood or blood products.

    h. The presumption that life should be prolonged where possible.

i. Although Mrs W has dementia, she is mobile, able to converse with others, generally physically well for her age and, if she were to survive her current acute illness, is likely to be able to derive some pleasure and comfort from living during her remaining years.

63. In all the circumstances I am satisfied that it is in Mrs W’s best interests to have blood transfusion to restore and maintain her haemoglobin at 10 g/dl. I so conclude doing my best to put myself in her shoes and determine her interests taking into account her welfare from the widest perspective. I am satisfied that the decision is in Mrs W’s best interests is lawful and in accordance with her human rights under articles 2, 3, 8 and 9 of the ECHR.

64. This judgment explains the decision I made at the out of hours hearing. I have already made an order at the hearing declaring that Mrs W lacks capacity to conduct the proceedings and to decide whether to consent to treatment for her severe anaemia by blood transfusion, that the advance decision dated 29 November 2001 is not valid, and that it is in Mrs W’s best interests to receive blood products to restore and maintain her haemoglobin to 10 g/dl. I also ordered that arrangements for Mrs W’s care and treatment as authorised were lawful and proportionate provided always that any measures that may be used to facilitate such treatment shall be the minimum necessary and all reasonable steps are taken to minimise distress to her and to maintain her dignity. The order allows for any party to apply on notice, such application being reserved to me if possible.

65. I conclude by expressing my gratitude to all involved in the hearing, including the out of hours clerk, the medical witnesses, solicitors, counsel and Ms W and Ms J. The hearing was conducted with remarkable calm given the late hour, the urgency of the circumstances, the opposing views expressed about the validity of the advance decision, and the profundity of what was at stake. Ms Kohn had rapidly produced a most helpful position statement. The Official Solicitor had very little notice of the application and hearing but, with Ms Khalique QC, provided invaluable assistance to the court in scrutinising the evidence available. This case provides another example of the invaluable benefit of the Official Solicitor being rapidly available to participate in out of hours hearings.

66. I wish Mrs W and her family well as she deals with her current, acute condition.