



IN THE HIGH COURT OF JUSTICE

No. COP12143373

FAMILY DIVISION

[2012] EWHC 1390 (Fam)

Royal Courts of Justice

Tuesday, 1st May 2012

Before:

MRS. JUSTICE THEIS

THE X PRIMARY CARE TRUST

Applicant

and

(1) XB

(By The Official Solicitor as Litigation Friend)

(2) YB

Respondents

MR PARISHIL PATEL (instructed by Mills and Reeve LLP) appeared for the Applicant Primary Care Trust

MR MICHAEL MYLONAS QC and MR CONRAD HALLIN (instructed by the Official Solicitor to the Senior Courts) appeared for the Respondent XB

MR MARK MULLINS (instructed by Irwin Mitchell, Solicitors) appeared for the Respondent YB

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J U D G M E N T

(As approved by the Judge)

MRS. JUSTICE THEIS:

Introduction

1. This matter concerns an application by the XPCT for declarations under s.26(4) of the Mental Capacity Act 2005 (“MCA 2005”) as to the validity of an advance decision made by XB on 2nd November 2011 that he wished, amongst other things, to have his ventilation removed in certain defined circumstances.
2. The matter was listed before me at very short notice, pursuant to orders made last Friday by Mrs. Justice Macur, to consider the following matters:
 - 1) XB's current capacity to communicate his decision as to the continuation of life saving treatment.
 - 2) Whether the advance decision was entered into by XB on 2nd November 2011 and if so, whether it was valid and applicable.
 - 3) Whether the advance decision, if entered into by XB on 2nd November 2011, was intended to be time limited to 2nd May 2012.
3. XB is a party to these proceedings and is represented by the Official Solicitor as his litigation friend. Following assessments over the weekend by a consultant neurologist, Dr. M, and JP, an experienced speech and language therapist, there has been no issue on the evidence before me, or between the parties, that XB now lacks capacity to communicate his views as to the continuation of life support or to conduct the litigation.
4. The clear evidence, which I accept, is that this lack of capacity is permanent. This was confirmed by the oral evidence of the very experienced speech and language therapist who gave evidence yesterday. I have also seen the three video clips that have been prepared of the assessment that took place last Saturday, which clearly and vividly demonstrated to me the conclusions reached as to XB's current capacity.
5. XB's wife, YB, is a party to these proceedings and is represented by Mr. Mullins, Counsel. She has attended court, together with her son and daughter. XB's GP and one of his carers were also made parties by virtue of the order of Mrs. Justice Macur on 27th April. I have discharged them as parties, as I could see no purpose in them being parties to the proceedings. It is accepted that they are witnesses of fact.

6. Although this hearing has been held in public, I have made a Reporting Restrictions Order, the effect of which is to prohibit the reporting of any information that may lead to the identification of XB, or of any of the persons named in the schedule attached to that order. In delivering my oral judgment I am using the full names, rather than the somewhat impersonal initials that have been used in the papers. Any reporting of my decision must comply with the terms of the Reporting Restrictions Order.

The Law

7. The relevant statutory provisions of the MCA 2005 are as follows:

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.*

Background

- 8. XB suffers from Amyotrophic Lateral Sclerosis: Motor Neurone Disease, which was diagnosed in January 2001, when he was only 57 years of age. Save for a hospital admission in 2003, he has continued to live at home. During the hospital

admission in 2003, he had a tracheotomy and for at least 8 years his breathing has been assisted by an invasive ventilation device which involves a tube being passed into his windpipe.

9. A patient with long term invasive ventilation is unable to talk. XB has been able to communicate by varying different means, most latterly by movement of his eyes to the right to indicate that he agreed with the question that was being asked of him. Prior to that, he was able to use a communication board as well. The communication board contained the letters of the alphabet and the word "yes" and "no". XB was therefore able to both answer questions which required a yes or a no answer but also to spell out his more particular thoughts and feelings.
10. I understand the term used by the family and those who cared for XB for his ventilation device (that he has had since 2003) has been 'Nippy'. It derives, I think, from the acronym for non invasive positive pressure ventilation device (NIPPV), even though that is not actually what it is. He actually has an invasive device. The description given for this device has varied in the documents; for example, the description given by the XPCT in the continuation form attached to their application and in the advance decision itself. But, in my judgment, the oral evidence is abundantly clear (in particular from the GP XW) that what was being referred to is the ventilation device they call 'Nippy', which XB has had for the last eight years.
11. The PCT commissions care for XB, but the actual delivery of his care is carried out by his general practitioner, XW, and carers employed by an independent care Agency. His family, in particular, his wife YB, are closely involved in the delivery of his care. Through their efforts and dedication, they have been able to respect his wishes to be cared for at home, despite the high level of care that he clearly requires.
12. The question of what life sustaining treatment XB wished to receive had been discussed with him on a number of occasions, dating back to at least 2010, and appropriate advice had been taken at various stages by XW, the general practitioner, and others. At points in 2010 and 2011, XB had indicated that he wished to have such treatment withdrawn, but he had not expressed such a wish in what was considered to be a consistent form.
13. On 2nd November 2011, he made an advance decision to refuse treatment. XW, who has been his general practitioner since 1993, made a statement and gave oral evidence to me about the build-up to this being done, and the discussions he had had with XB and others about this. For example, at a meeting in August 2011, XB had expressed the wish for his ventilation device to be removed that day. It was explained to him that that could not be done, but that arrangements would be made to prepare an advance decision. This was initially drafted by AW, a mental capacity co-ordinator who had been contacted by the general practitioner,

following the general practitioner attending a talk AW had given. The draft was discussed with YB and XW. It was felt it needed simplifying to enable it to be explained to XB. A further simpler document was prepared, using a pro forma template that YB had been able to locate on the internet.

14. This background in relation to the advance decision being made on 2nd November 2011 is independently confirmed in the statements that I have seen from YB from AW. The relevant part of the advance decision reads as follows:

"I have been diagnosed with motor neurone disease (MND-ALS). I am becoming progressively weaker. This has affected my respiratory system. I need support from NIV. Feeding I have a PEG. Stoma/catheter for elimination, and most importantly my ability to communicate, which I now do with my eyes + communication board. I have discussed with my family my feelings and this is the right time to make a decision about the way I die. I know my condition is terminal. I wish to express my choices".

15. A little later in the document, it continues under the part entitled *"I would wish to refuse life sustaining treatment, even if my life was at risk"*. Firstly, in the left-hand box it states *"Removal of non invasive ventilation (NIV)"*, and records that this should be done in the following circumstances:

"In the event that my disease progresses to a stage where I am unable to communicate my needs and lose the ability to have any control over my decisions of my care and management. I fully understand the implication of the advance decision, and appreciate the consequences and it would put my life at risk. I consent to have relevant treatment before and after NIV removal to prevent me from becoming distressed or experiencing pain. However, apart from the above, I would not wish to have any life prolonging treatment, including my PEG feed".

16. This document was agreed to by XB, with his wife YB, XW, his general practitioner, and AW, the mental capacity co-ordinator, in attendance on 2nd November 2011. One of the carers was also there. It is thought it was a carer called L, but the evidence demonstrates that carer took no active part in the preparation or involvement of this document.
17. On 2nd November 2011, seeking XB's views in relation to this document was done as a collaborative process by those who were there, whereby it was read out to him, and then each part was dealt with and questions were asked in a way to find out if XB consented. His consent was communicated by movement of his eyes.
18. XW took the lead in relation to this aspect, and he gave detailed oral evidence to me of the care that was taken in this process to ensure the terms of this document accorded with XB's wishes. His evidence, in my judgment, was very clear that it

did so. The view is re-enforced by XW's evidence of other occasions when he had visited XB on other issues, he had noted that XB had been tired or had been unable to express himself clearly about what he wanted to be able to communicate. On those occasions XW said he had left it, not pursued the matter in hand, and had returned on a future occasion to get the relevant information. In my judgment XW, although not experienced in relation to motor neurone disease, is clearly somebody who not only knows XB well, but has also experienced communication difficulties in the past and dealt with those in an appropriate way.

19. XW felt that, due to the time that he has known XB and his experience in dealing with him, he was confident that XB understood and agreed to what is set out in the advance decision on 2nd November 2011. Again, this careful process is independently confirmed in the detailed statements from YB and AW.
20. In places, the terms of the advance decision that was agreed to by him and signed on his behalf by YB and witnessed by XW and AW are not always clear. But I am satisfied it is more likely than not on the evidence I have read and heard that that does not undermine what XB intended; for example, the term 'non invasive ventilation' was not in fact what XB was having, according to the report of Dr. McN, a Consultant in Palliative Medicine. He has invasive ventilation, and has had this since 2003. But XW was very clear in his oral evidence that what was being discussed with XB in his presence and what he agreed to was the removal of his 'Nippy' device, which is the invasive ventilation he has had for over eight years. I unhesitatingly accept XW's evidence in relation to that aspect.
21. This application was made by the XPCT due to concerns they had about the circumstances in which the advance decision was signed. This arose from the XPCT being alerted by one of XB's carers as to the circumstances in which the advance decision was made.
22. For reasons which I have not gone into (as it was not been necessary to for the purposes of this hearing) it took over a month to convene a meeting to consider the issues raised; that meeting took place last week on 23rd April. One of the carers who attended that meeting raised concerns about whether XB did communicate his agreement to the advance decision by movement of his eyes, which she said she did not see.
23. I directed at the start of this hearing that a full statement was taken from this witness. On receipt of that statement during the hearing yesterday, three things became very clear:
 - 1) In fact, this carer was not present on 2nd November 2011.
 - 2) The matters referred to in her statement, although she cannot remember the date, are very unlikely to have taken place after 2nd November 2011.

- 3) In any event, she accepts in that statement that on the occasion she was referring to she was not in a position to see eye movements, as she was on the left-hand side of the bed.
24. The evidence points to another carer being present on 2nd November 2011. That is supported by the GP records and by the duty roster I have seen. No concerns have been raised by the carer who was present on 2nd November 2011 as to the circumstances in which the advance decision was entered into.

Decision

25. Therefore, on the evidence, I am entirely satisfied that XB had capacity to make the advance decision on 2nd November 2011, and that it complied with all the necessary formalities to be an effective advance decision.
26. The only other matter that I need to consider is that, at the end of the advance decision in the box entitled "Review 1", the date of 2nd May 2012 has been put by the "Date of review", and 2nd May 2012 has also been put by the part that says "Valid until". This raises the issue as to whether this decision is time limited and ceases to have effect tomorrow.
27. XW in his evidence was clear that this was not raised with XB, other than in the general context of keeping the advance decision under review. YB says in her statement:

"I do not recall that dates were discussed with XB or put to him. He certainly did not agree that there should be a date in the future when the decision would become ineffective"

28. In AW's statement filed this morning he said he had a clear recollection of the meeting, and is confident that they did not discuss the "valid until" date with XB. He continues in that statement:

"I am also not sure what the purpose of this date is. I can remember going through the handwritten contents of the draft and the final document with YB, but did not spot that there was a 'valid until' date, and I certainly did not realise this could be an end date to the advance decision. In fact, I have never seen it before in an advance decision".

29. I am satisfied on the evidence I have read and heard that XB did not agree to this advance decision to be time limited to 2nd May 2012. This was not something that was discussed with or agreed to by him. I am satisfied that the dates are in there in the context of keeping the advance decision under review. This is, in fact, what took place when XW visited him on a number of occasions earlier this year. On

those occasions XW was able to communicate with XB about his advance decision, he was clear in his statement that the document on 2nd November still accorded with XB's wishes. Therefore, I will declare that the advance decision dated 2nd November 2011 is not time limited.

30. I am enormously grateful to all those who have made such herculean efforts to ensure that this hearing could be effective. That has included a considerable amount of work being undertaken over the weekend. I note the statement from AW emailed through overnight was done so in the early hours of this morning. These efforts have enabled the court to reach a decision without delay; this enables the family and those who support them to deal with the consequences that flow from my decision.
31. As YB movingly describes at the end of her statement, her husband was a lover of life, so much that he wanted to live as long as possible even after his diagnosis. Decisions around end of life are not easy for someone who has loved life so much. She said the progression of her husband's motor neurone disease has been such that he has been forced to come to terms with the fact that his quality of life has deteriorated significantly, to the extent that he lost control over the most basic aspects of his life because he cannot communicate any more. She said, having seen the report from Dr. M, who concluded that her husband's inability to communicate is permanent, this is the position her husband wanted to avoid, and the way he wanted to avoid it was by being allowed to peacefully end his life. This was why, after careful consideration, he reached the decision to agree to the advance decision. This was a decision that had the support of his family, and can now proceed in accordance with XB's wishes.
32. In relation to wider points raised by this case, there are only three points I would wish to make.
33. Firstly, in the event that there is an issue raised about an advance decision, it is important it is investigated by the relevant health authorities or relevant bodies as a matter of urgency. This will clarify issues at an early stage. It will enable relevant primary evidence to be gathered (for example, by taking statements) and, if required, an application made to this court. The judges who sit in the Court of Protection are experienced in dealing with urgent applications, as this case has demonstrated.
34. Secondly, there is no set form for advance decisions, because the contents will inevitably vary, depending on the person's wishes and situation. The Mental Capacity Code includes guidance on what should be included in an advanced decision at paragraphs 9.10 to 9.23. At paragraph 9.19 the Code lists matters that it is helpful to include in an advance decision. They are set out below:
 - *full details of the person making the advance decision including the date of birth, home address and any distinguishing features;*

- *the name and address of the person's GP and whether they have a copy of the document;*
- *a statement that the document should be used if the person ever lacks capacity to take treatment decisions;*
- *a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;*
- *the date the document was written;*
- *the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence);*
- *the signature of the person witnessing the signature, if there is one.*

The Code also lists matters in relation to an advance decision if it is dealing with life sustaining treatment at paras 9.24 and 9.28. They are set out below:

9.24 The Act imposes particular legal requirements and safeguards on the making of advance decisions to refuse life-sustaining treatment.

Advance decisions to refuse life-sustaining treatment must meet specific requirements:

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

9.25 Section 4(10) states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations

antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life.

9.26 Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural mechanisms that control hunger and thirst and requires clinical monitoring. An advance decision can refuse ANH. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.

9.27 It is very important to discuss advance decisions to refuse life-sustaining treatment with a healthcare professional. But it is not compulsory. A healthcare professional will be able to explain:

- what types of treatment may be life-sustaining treatment, and in what circumstances*
- the implications and consequences of refusing such treatment (see also paragraph 9.14).*

9.28 An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth. Section 5 of the Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity to consent (see chapter 6). An advance decision can refuse artificial nutrition and hydration.

35. Thirdly, there are number of pro forma advance decisions available on the internet. One of the difficulties in this case was the inclusion in the pro forma of a 'valid until' date. Those organisations that have such terms in their pro formas may want to look again at the necessity for that being in the pro forma form. It is clearly in the interests of the person who has made the advance decision, his or her family, and those who have responsibility for providing or withholding treatment that there is clarity in relation to what the terms of the advance decision are.