



Neutral Citation Number: [2021] EWCOP 16

Case No: 13718828

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

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 23/02/2021

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

Between :

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	<u>Applicant</u>
- and -	
NZ	<u>1st Respondent</u>
(by her litigation friend the Official Solicitor)	
- and -	
MA	<u>2nd Respondent</u>
- and -	
RZ	<u>3rd Respondent</u>

Miss Sian Davies (instructed by **Browne Jacobson**) for the **Applicant**
Miss Debra Powell QC (instructed by **NZ's litigation friend, the Official Solicitor**) for the **1st Respondent**
Mr Karim QC (instructed by **Enoch Evans LLP**) for the **2nd and 3rd Respondent**

Hearing date: 23rd February 2021

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered following a remote hearing conducted on a video conferencing platform and was attended by members of the public and the press. 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 Hayden :

1. This is an urgent application brought by the University Hospitals of Leicester NHS Trust. It concerns NZ, a woman in her early thirties, who is gravely ill with pneumonitis, an inflammation of the lung tissue, caused by Covid-19. NZ is suffering several other medical complications in consequence of the inflammation. The applicant Trust seek declarations, pursuant to section 15 of the Mental Capacity Act 2005, first, that NZ lacks the capacity to make decisions about her care and treatment: second, that it would not be in her best interests to continue to receive life-sustaining treatment by way of the extracorporeal membrane oxygenation machine, (ECMO). The Trust propose a palliative care regime.
2. The application is supported by the Official Solicitor, but it is opposed by NZ's husband, MA, and by her sister, RZ, both of whom are represented by Mr Sam Karim QC. The Official Solicitor, represented by Miss Debra Powell QC, sought to be joined as litigation friend to NZ, and I granted the application.

Factual background

3. NZ grew up in Nottingham. Now in her early 30's, she has manifestly been highly committed to her family. She has been married for 6 years, has a three-year old daughter and, in circumstances I will set out below, gave birth to a son only a few weeks ago. NZ and MA were married by arrangement and have enjoyed a happy marriage.
4. Last year NZ became pregnant. I was told by her sister, RZ, that she discovered, during her pregnancy, that she was carrying a boy. This, RZ told me, was exactly what her sister wanted, *'it completed her family'*. She concealed this private joy during the pregnancy, but only so that the delight would be even greater to her husband and family.
5. NZ was extremely close to her young daughter and, I have been told, proud of her home. She was a highly conscientious mother and much involved with her sisters and their children. I have been told by RZ that her sister was a religious woman, praying five times a day and for whom her faith was important. I accept that evidence.
6. In the past, NZ was diagnosed with an autoimmune condition, Addison's Disease, and antithrombin-3 deficiency, which affects blood clotting. That background caused her to be anxious about her own vulnerability to the Covid-19 virus. I have been told that *'nobody could have tried harder'* to be 'Covid-safe' than she was, and that she took very great care to keep social distancing guidelines. But this is an insidious virus, and NZ contracted it in January this year. I am told that she was deeply fearful of the virus and had somehow sensed she would be vulnerable to it. She had, her sister told me, contacted the NHS health line, when she first became unwell and was advised to rest and take care of herself. According to her sister, her condition worsened, and she was worried that if she went in to hospital she might not come out. I do not know, nor can I evaluate, the accuracy of this, although I do not, for a moment, doubt the sincerity of the perception. What is clear is that NZ's condition deteriorated dramatically. She was admitted by ambulance to hospital on 20th January 2021.
7. NZ's breathing difficulties were already significant by the time she arrived at hospital. She was diagnosed with pneumonitis secondary to Covid-19. This causes severe lung damage and significant destruction to the lung tissue. Its consequence is, I have been

told, that it prevents the lungs from delivering sufficient oxygen to the blood. It makes it very difficult to breathe, and it causes the sensation of shortness of breath. It is profoundly uncomfortable and frightening for the patient.

8. By the time of her admission, NZ was 32 weeks pregnant. Her treating clinicians were concerned that her pregnancy might be exacerbating her difficulty in breathing, due to the enlargement of the uterus. The following day a decision was made to deliver NZ's baby by emergency caesarean section. Because she had known that she was carrying a boy, she had already selected a name for him, MZ, which he now bears. Following the delivery of her son, NZ's condition continued to deteriorate and within a short time, her oxygen levels became dangerously low.
9. It was necessary, within 48 hours of her admission to transfer NZ to an intensive care unit. This took place on 22nd January 2021. Mr H, Director of ECMO, commenced a number of treatments. He gave evidence before me and filed a statement, dated 23rd February 2021. I found his evidence to be kind, reflective and unwaveringly focused upon his patient. Mr H is the clinical lead consultant for ECMO, which is a highly specialised area of medicine. He has held that post for 9 years. The ECMO essentially involves oxygenating a patient's blood; unlike a ventilator, it provides a mechanical ventilation that does not superimpose breathing on a patient but allows a patient's own breathing to be supported. For NZ an accompanying sedative regime was put in place to help repress her periodic agitation and discomfort. Pain relief, by morphine, has also been given, as well as anti-biotic and anti-fungal medication, designed to reduce the risk of almost inevitable infection.
10. Mr H told me that extracorporeal membrane oxygenation is effectively a *'last resort'* treatment. I had the firm impression that, for this 32-year-old woman, in this most tragic of circumstances, he had wanted to try anything that was possible. The supported ventilation responding to the patient's own breathing is designed to enable the patient to rest, so that their lungs can have the opportunity to recover from damage and scarring. In that sense, it is not a proactive treatment; it is designed to help the lungs recover. In order to provide it, cannulas are inserted into the patient's blood vessels to enable blood to be transported from the body into the ECMO machine, a process which Mr H referred to as a cycle.
11. He further explained that due to the nature of the treatment, ECMO has, at least until recent times, only really been considered as a viable option for patients who are otherwise regarded as fit, prior to their admission. It is rarely administered to those over the age of 70, as those in that age group have diminished lung capacity and is only generally used for patients whose clinical condition places them at a 40% (or lower) chance of survival, despite having received all other intensive care treatments. During the course of the pandemic, the use of ECMO has increased approximately by a third. On average, 25% of patients do not recover. However, those patients who are placed on ECMO in consequence of conditions which are sequelae of symptoms arising from Covid-19 infection, have lower success rates than previously seen with other conditions. Mr H emphasises that there are a range of factors to take into account, he observed that fewer than 50% of ECMO patients have been recovering in this second wave of the pandemic.
12. During the course of NZ's treatment on the ECMO machine, there have been regular CT scans. A scan taken on 10th February 2021 showed that NZ's pancreas had ceased

to function, part of her left lung had died, and the remaining lung tissue had become '*densely consolidated or collapsed*'. In addition to the death of those parts of the left lung and the remaining lung damage, there are signs of pneumothorax and evidence of pooling of blood, caused by the invasiveness of the ECMO procedure.

13. Mr H considered that NZ's situation is to be regarded as '*extremely grave*'. During the course of last week, there was a recognition, within the clinical team, that the time had come to provide for a final visit for the family. In the intensive care unit, in the present circumstances, this requires careful planning. Earlier in the pandemic such visits were frequently impossible to arrange.
14. The clinical team consider NZ's condition to be precarious. There has been discussion with the family. Mr P, a consultant in intensive care, has spoken with the family; so too have Dr D and Dr S. There was a belief, and a hope, that the doctors and the family were progressing towards an agreement as to the way forward. But as the days passed, that consensus, if it was ever there, evaporated. Because of the escalating gravity of NZ's situation, the Trust have made their application this afternoon to have withdrawal from the ECMO declared as being in their patient's best interests.
15. A CT scan, taken on the 15th February 2021, showed no further improvement in lung condition, and a yet further deterioration in the condition of the pancreas. Mr H explained that a patient in NZ's condition requires a high degree of intensive care. This, NZ does not find easy to accept. She becomes agitated and displays signs of discomfort. Many patients receiving ECMO, Mr H tells me, are alert enough to communicate. NZ, however, is described as being in a '*pharmacologically induced coma*'. There have been multiple attempts to reduce the level of sedation, but whenever this has been attempted, it has led to a significant reduction in NZ's blood oxygen levels and to her increased distress, exhibited by visible grimacing. In the absence of any prospect of recovery her present circumstances are irreconcilable with any clinical evaluation of her best interests.
16. On the 15th February 2021, a multi-disciplinary meeting was convened, and there was a unanimous conclusion that the focus of NZ's treatment could no longer be the preservation of her life, but should move to palliative care, intended to promote her comfort and her dignity. Mr Karim pressed Mr H on the analysis that underpinned the conclusion of the clinical team. He identified four central aspects to his reasoning: Firstly, NZ's lungs, for the reasons he described, and which I have set out above, have become too fragile to withstand any further surgical intervention. This presents a high risk of bleeding and to a degree that would be both fatal to her and very distressing. Getting the balance of the clotting functioning right, with the heparin medication, has become a delicate and risky process. Secondly, NZ's overall condition has now so deteriorated as to permit no realistic chance of recovery. Mr Karim pressed as to whether there might be a slim or vestigial hope but Mr H, considered that the prospect is, as he put it, '*zero*'. Thirdly, Mr H considered that the continuing connection to the ECMO machine places her at risk of both a fatal bleed and a potentially distressing death.
17. Mr Karim asked Mr H whether he could be sure that NZ is experiencing pain. Mr H explained that he had observed that if any pressure is placed on NZ's abdomen she responds by grimacing. He considered that was probably due to the pancreas damage

and the fluid collection. NZ has not been in any way able to communicate verbally, since her admission to ICU.

18. Recognising that the conclusion of the clinical team would be difficult for the family to accept, and no doubt driven by the instinctive need to pursue all options for any patient, but particularly a 32-year-old mother of a very young baby, a second opinion was sought. Professor A was consulted; he is a Professor of Respiratory Medicine and Intensive Care. Sadly, he agreed that there is evidence that NZ's lungs have continued to deteriorate despite the ECMO treatment and concluded that there is no chance of her recovering.
19. Mr H explained that there are patients who stay longer on the ECMO machine than NZ has yet done. But they are all patients in whom a trajectory of improvement is identified relatively quickly. He told me that, having regard to the views of the clinical team and to the second opinion from Professor A, he had come to the conclusion that he had passed a stage where he was seeking to preserve his patient's life, but had reached a point where he was, in reality, '*prolonging her death*'. Though he expressed himself in sensitive terms, he signalled, to my mind, unambiguously, that he had reached a threshold beyond which further treatment would be professionally unethical.
20. NZ's husband and sister take a different view. This is not grounded in any real difference as to the medical situation; it is, for them, a conflict between a religious belief, genuinely and devoutly held, and medical science. It is a conflict which cannot be reconciled. To condone any act that would be seen to bring life to an end would, the family believe, be inconsistent with their faith. They recognise the medical evidence and engage with it. In particular, they accept that continuation of treatment may cause NZ to suffer but consider that such suffering is the will of God and attracts God's love. MA told me that such suffering is to be welcomed and that NZ would welcome it. It is through suffering that we know God, he explained. This principle echoes not only throughout Islam, but throughout the whole of the Judeo-Christian tradition. It poses real ethical dilemmas for those who understand their faith in these uncompromising and uncompromisable terms. I do not doubt that these are the genuinely held beliefs of NZ's husband. Her sister also articulated them with equal force, though I note she required to be prodded to do so by her brother-in-law. I think it is likely that NZ, had she confronted this dilemma, would, in principle, have expressed the same religious view as her family. I am quite sure that she would have wanted to do all that she could to be with her children.
21. Evaluation of 'best interests', as all counsel have impressed upon me, is not confined to medical opinion alone, nor religious beliefs in isolation, nor even an assessment of wishes and feelings. Identifying best interests requires the broad canvas of NZ's life, circumstances and needs to be considered in their totality. Alongside this it must also be recognised that a court will never seek to compel or encourage a medical professional to act in a way that he or she considers unethical. The central imperative in medicine is to do good. Here the medical evidence establishes that continued ECMO treatment would achieve no benefit and cause continuing, potentially escalating, harm. I accept that evidence.
22. The applicant's care plan proposes arrangements for the family to be with NZ at the end of her life. It involves instituting palliative care and '*anti-anxiety medication*'. The clinical team hope that it will be possible for NZ to die with her family around her, with

her religious observances respected and in as much comfort as can be found for her. In this way they consider her dignity can be promoted and respected. I agree.

23. Mr Karim submits that NZ's wishes, were she able to express them, would be that she would prefer to undergo distressing treatment in the hope of seeing her children again. As I have said above, I accept that. Mr Karim argues that an adjournment of 48 to 72 hours to obtain a further opinion as to the futility and prospects of any treatment, along with a further CT scan to assess any developments would assist the family in coming to terms with NZ's situation and, he suggests, this is what NZ herself would have wanted. This cannot be reconciled with NZ's medical needs nor will it likely resolve the family's religious and ethical dilemma.
24. MA spoke movingly and lovingly about his wife. He and his sister-in-law expressed their visceral distress at the older child's sadness and confusion about what is happening to her mother. They described how she appears to take comfort by wearing her mother's shoes. Mr Karim has advanced his case with intellectual honesty and simplicity. He recognises and confronts the fact that this family seek a miracle.
25. Mr H told me that patients who are on ECMO machines frequently suffer blood clots in their lungs and develop deranged coagulopathy, which can cause fatal internal bleeding. This risk is heightened by the condition of NZ's pancreas, as is the risk of cardiac arrest. Continuation of treatment would be taking risks for no benefit.
26. Counsel have not addressed me, extensively, on the law. The law is settled and though easy to state is never easy to apply. In **Aintree Univ. Hosp. NHS Foundation Trust v James [2013] UKSC 67** at [22] Baroness Hale observed:

"...the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."

27. Further, at [36] of the same judgment:

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

28. As I deliver this judgment, I am acutely aware that I do so within 24 hours of the Government setting out what has been described as ‘the roadmap’, by which it is hoped some of the more devastating impacts of the Covid-19 pandemic may be put behind us. The profoundly sad circumstances of this family illustrate that there is still further to travel.
29. This is a young woman whose life and hopes have been extinguished by this insidious virus. It is a tragedy of almost unbearable dimension. A young family split apart prematurely; their grief is raw and palpable. It is almost beyond human empathy; the pain is so obvious and visible that there is an instinct to seek to recoil from it. As I have set out, the care plan contemplates that NZ and her family will be together at the end. It is structured to avert further pain and its central premise is to promote NZ’s dignity at the end of her life. The objective here is not to shorten her life, but as Mr H has, in my judgment correctly identified, to avoid the prolongation of her death. NZ will have her husband and family with her at the end. That is a right that many have, of necessity, been denied in the last 12 months. Their loss has underscored the importance of this final contact for those for whom it can be achieved. I should like to say finally, that RZ and MA could not have expressed themselves more forcefully, sincerely or with greater eloquence. They could have done no more for their wife and sister and I hope that brings some peace for them.
30. In all the circumstances therefore, I consider it right to grant the declaration sought by the Trust, in the terms drafted.